

**An examination of experiences of mothers of children
With Down syndrome: A two country comparison**

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requirement for the degree of Doctor of Philosophy
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Dedicated

To my family, and all whose efforts have enabled
children with Ds achieve their potential

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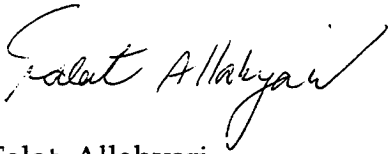
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DECLARATION

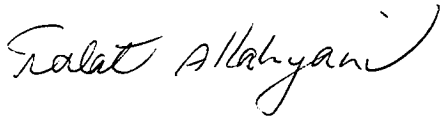
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A handwritten signature in black ink, appearing to read 'Talat Allahyari', with a stylized flourish at the end.

Talat Allahyari

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ACRONYMS AND ABBREVIATIONS

ABS	Australian Bureau of Statistics
DS	Down Syndrome
IDEA	Individual with Disabilities Education Act
IQ	Intelligence Quotient
NDA	Not Diagnosed with Anything
NQOLP	National Quality of Life Project
NUDIST	Non-numerical Unstructured Data Indexing Searching and Theorising
OECD	Organisation for Economic Cooperation and Development
OT	Occupational Therapy
QDA	Qualitative Data Analysis
QOL	Quality Of Life
SRV	Social Role Valorisation
TWC	Third World Countries
WHO	World Health Organisation

An examination of experiences of mothers of children With Down syndrome: A two-country comparison

Abstract

The focus of this study is the experiences of mothers of children with Down syndrome (Ds) and the provision of social services for their children and their families. Children with Ds have a range of physical and intellectual differences. This study examined the living conditions and quality of life of children with Ds based on mothers' perceptions about social services and their experiences of having a child with Ds. A two-country comparison of the differences in the availability of resources such as social services was made. The areas of health and education were selected as primary social services.

The nature of the problem prompted a qualitative, interpretive approach to the study through the use of case studies, interviews and survey methods to produce practical solutions to the problem. The sample consisted of 68 mothers of children with Ds, who experienced the difficulties of raising their children. Data were coded by NUDIST to produce the headings: family, services, mothers' perceptions, and satisfaction with services. Descriptive analysis indicated four main areas determining the living conditions of children with Ds and their unmet needs.

The findings of the study revealed that there are major barriers preventing children with Ds from achieving a normal life. These barriers included the negative attitudes of health and education professionals; a lack of accurate information about Down syndrome; inappropriate social services; the current practices of informing mothers about their child's diagnosis; and difficulty in accessing information about Down syndrome and social services. As a result, it is suggested that there is a need for a new understanding about Ds, which requires re-education and up-to-date information for health and education professionals, mothers, and society in general.

Clearly, the range and quality of social service programs offered by authorities in the Ministries of Health and Education in both Australia and Iran need to be reviewed. The conclusion drawn from the examination of experiences of mothers in Australia and Iran indicated that contrary to the literature, mothers' emotional problems are not natural feelings and could be prevented if professionals changed the traditional way of pointing out the negatives, and instead, emphasise the potential and possibilities of a child with Ds. The research generated a background report for the Australian and Iranian Ministries of Health and Education with the intention of contributing to an improved quality of life for children with Ds.

Chapter 1.0

The Research Context

1.1 Chapter Overview

The focus of this research is the experiences of mothers of children with Down syndrome (Ds) and the provision of social services for their children and their families. The aim is to study the living conditions and quality of life of children with Ds, based on parents' perceptions about social services, and their experiences of having a child with Ds. The overall intention is that this research will result in improvement in the quality of life for children with Ds. In this chapter the research problem is introduced. The theoretical rationale is presented. Key terms used in the thesis are defined and examined. The significance and contribution of the research are identified and an outline of the presentation of the study is provided.

1.2 Research Problem

This research examines the provision of current social services for children with Ds and their families. Children with Ds form the largest identifiable group within the category of children with mental disabilities (Shepperdson, 1988). According to data collected by UNICEF, one child in every ten is either born with, or acquires, a physical, sensory or mental impairment (UNICEF, 1995). The population of children with disabilities today estimated at 150 million, is larger than ever (UNICEF, 1995). There are different causes that lead to a disability. A 1986 United Nations questionnaire in clustered causes of disability into four categories:

- genetic and hereditary factors,
- biological factors (disease),
- accidents, and
- socio-cultural and environmental conditions (p.10).

For the purpose of this study Ds is considered within the area of a disability caused by genetic and hereditary factors. Down syndrome is also conceptualised as a social and political issue rather than "personal troubles" (Fulcher, 1988).

A review of the international and professional research literature will reveal that social services are considered largely inadequate for children with Ds and their families, particularly in emerging countries. A child with Ds is often perceived as a "problem" both within the family and in society. For example, Pueschel (1993a), one of the leading medical authorities in the field of Down syndrome comments: "while I was training as a paediatric resident at Montreal Children's Hospital, my son Chris was born. My wife and I were initially devastated when we were told that Chris had Down syndrome" (p. 26).

A critical issue that often develops is the labelling of children with Ds as mentally disabled and they are seen as socially devalued. Wolfensberger (1972) developed the principle of normalisation and asserted that devalued people are often segregated from the rest of society. The result is that the segregation and labelling has a negative effect on the attitudes of other people, as well as a negative effect on the mother's reaction towards her child with Ds. In fact it has been asserted that, some parents wish that their child "had not been born or was dead" (Cunningham & Sloper, 1983, p.20). Therefore, negative labelling and negative attitudes will most likely affect a child's life adversely, which in turn creates other problems in relation to their quality of life.

Often family members of a child with Ds, especially mothers, may feel guilt and shame when a child with a disability is born. This response has been highlighted by Sharifzadeh (1992) who noted these feelings in a Middle Eastern family and remarked that guilt is felt most often by the mother who is usually held responsible for the birth of a child with a disability. In this particular culture, shame can also be felt by the father who often views his child's disability as a personal defeat on the family's pride. Cunningham and Sloper (1983) revealed that these feelings are

common not only in Middle Eastern families but in Western families as well. The parents' initial reaction to the news about their baby's diagnosis of Down syndrome is often based on ignorance and misinformation. For example a false belief was that all people with disabilities were potential criminals. A report by Brinkworth (cited in Stratford, 1989) revealed that residents of a village in North-east England protested at a proposal for a group home for people with Ds, and told a local planning committee that "all grades of Mongols have committed murder and acts of violence. This was in 1984!" (p.42).

The main problem faced by children with Ds is intellectual disability that affects their learning ability. Therefore, one of the key terms to be defined is "disability" in the context of its link to social services. Nevertheless the degree of intellectual disability may vary from mild to moderate or severe. Moreover, there is no relationship

"between the number of physical characteristics present in a child with Ds and his/her intellectual development. Those with obvious physical features can be among the least disabled intellectually"(Aagaard, 1990, p. 2).

In summary, Down syndrome is largely considered to be a significant disability where the disabled are often devalued and segregated from the rest of society. As a result, this segregation has a negative effect on the attitudes of other people and adversely affects a child's development.

1.3 Theoretical Rationale

The central theme of this study is that children with Ds should achieve a normal life style. The 'theory of normalisation' presented by Wolfensberger et al (1972) and the social perspective of quality of life (Aiken, 1990; Blunden, 1988) in the context of socio-political theories of disability (Fulcher, 1988) underpin this study. Later, Wolfensberger (1983a) developed the principles of normalisation for all people with

disabilities. These principles are: de- institutionalisation of accommodation, access to work and leisure opportunities, and educational integration.

According to the theory of normalisation the social roles that people place on each other are powerful social influences. For example consider the following: the way people structure other people's physical environments; the activities that are offered, the language that is used with and about them, and other images and symbolisms. As a result, the role expectancies of children with Ds who are classified as disabled and socially devalued become negative ones.

One of the major strategies of the principle of normalisation is the power of imitation. Devalued people do not have the opportunity to model themselves on other people in society because they are segregated and grouped with other devalued people. Thus, segregation is not to the benefit of children with Ds.

Wolfensberger (1983b) asserted that relatively few people have found it possible to separate the different meanings attached to normalisation by various users of the term. He added that the most explicit and highest goal of normalisation "must be creation, support, and defence of value social roles for people who are at risk of social devaluation" (p.234). Valorisation refers to the "giving value to an object or mental representation" (p.236). Therefore, normalisation is also called 'social role valorisation'.

Quality of life is a broad concept. Since the 1950s, when 'QOL' was first introduced by Ordway (Musschenga, 1994) until the present, many authors such as Aiken (1990); Goode (1988); Parmenter (1992); and Schalock (1990); have made substantial contributions. Of three perspectives of quality of life; the philosophical, medical, and social perspectives of quality of life discussed by Aiken (1990), the social perspective of quality of life is a dominant paradigm in this study. Four dimensions of quality of life; physical well-being, cognitive well-being, material well-being, and social well-being (Blunden, 1988) are explored in chapter 3 in order to define quality of life of children with Ds.

Children with Ds should be given opportunities to lead a normal and longer life. Brown (1994) cited Berkman and Breslow (1989) who suggested that "mortality is delayed for individuals with active social lives" (p.239). Isolation does not have a positive outcome and a fulfilling social life for children with Ds is of paramount importance. Social theories in relation to disability (see Fulcher, 1988) underpin much of the context of this study and will be discussed in detail.

1.4 The Term "disability"

Undoubtedly, the way that we interpret disability depends on the knowledge and stereotyped assumptions that we acquire from our society. Historically, disability was seen as an individual problem (Fulcher, 1988). Until the 1970s, disability was closely related to the person and it was "the individual with a disability who has the problem and (thus) intervention aims to provide him or her with the appropriate skills to cope with it" (Oliver, 1986, p.16). In order to reduce the impact of societal attitudes concerning disability as an individual problem, attitudes towards disability were reconstructed. In recent years, policy makers and researchers have given a social dimension to its definition, known as social model of disability (Madden & Hogan, 1999). The social model of disability considers society responsible for not responding to people with a disability appropriately. An example of this can be seen in inappropriate living environments such as steps to the entrance of public buildings. A detailed examination of social theories of disability will be explored and developed in a later chapter.

The World Health Organisation (WHO) published the 1980 International Classification of Impairment, Disability and Handicaps (ICIDH) as a manual of classification relating to the consequences of disease. In WHO's international classification, health conditions are classified mainly in International Classification of Diseases, Tenth Revision (ICD-10), The functioning and disability associated with

health conditions are classified in ICIDH-2. According to this classification (WHO, 1999) which are adopted in this thesis:

Impairments: are problems in body function or structure as a significant deviation or loss.

Activity limitations formerly disability: are difficulties an individual may have in the performance of activities.

Participation restrictions formerly handicap: are problems an individual may have in the manner or extent of involvement in life situation (p.4).

According to the UNICEF (1995), using the above definitions, 10% of the world's child population has a disability or activity limitations. An important distinction in describing this population, should be between incidence and prevalence rates. Incidence refers to the rate of occurrence in a given population whereas prevalence refers to the number of persons with the particular disability within a total population (Serpell & Nabuzoka, 1991). For example, the incidence of Down syndrome is one in 660 live births universally. Since infant mortality is high in middle eastern countries where 182 children under one year die daily (UNICEF, 1993), the prevalence rate of childhood disability is lower than the expected number in those countries.

1.5 The Term "Down syndrome"

Down syndrome (Ds) is a congenital chromosome abnormality that results in intellectual and physical disability. Individuals with Ds have 47 instead of 46 chromosomes. At the outset it is important to note that Ds is still considered a disease by WHO (Madden & Hogan, 1999). On the other hand professionals like Stratford (1989) believed that Ds is not a disease but "part of our rich and varied biological inheritance" (p.8).

How we view a child with Ds depends on the knowledge that we acquire from our society as well as our negative or positive attitudes towards these children.

Children with Ds are different from other children physically and intellectually and in other ways. Due to these differences, the desired situation for children with Ds is not the same as for other children.

1.6 The Term "social services"

Social services have been classified in different ways due to different political and cultural circumstances. For example, Kahn (1973) believed: "social services exist to protect, to change, or to innovate with respect to many of the educational, child-rearing, value-imparting, and social induction activities once assumed by the extended family, the neighbourhood, and relatives" (p.29). This definition refers to the purpose of socialisation and development of social services. Morales and Sheafor (1992) discussed social services as one of three categories of social programs; social provisions, social services, and social action. They defined social services as:

programs that are designed to help people resolve problems or enhance their social functioning . These personal services include, for example, family and child welfare, marriage and family counselling, social services for children and the aged, social care for the handicapped, and information and referral services (p.107).

Many social services aim to contribute to the socialisation and development of different population groups including children or people with a disability. Mental health centers, child welfare centers, and hospitals provide therapy, help, rehabilitation and social protection. One of the important aims of social services is to facilitate access to resources, which meet the needs of consumers. These services may include programs such as information, advice, case advocacy, and legal services. Morales and Sheafor concluded that social service provisions should exist to answer the fundamental needs of people. These needs may be tangible such as food and clothing, or social actions, which allow people to change those circumstances that cause problems, such as discrimination, or unfair conditions.

The question of who is to be served and when services should be presented, leads this discussion to a philosophical point. Russo and Willies (cited in Morales & Sheafor, 1992, pp.104-105) indicated two approaches; selective and universal. The selective or residual definition of social services is based on the assumption that family and the market economy are sources to meet a person's needs, and only if these sources fail, should social programs intervene temporarily. The universal definition of social services is based on the assumption that due to social changes, needs change and therefore social programs respond to meet these changing needs. Thus, the definition of social services depends on our definition of social institutions.

1.7 The Significance and Contribution of the Research

Research in the area of Ds will contribute to and enhance the current knowledge base and benefit children with Ds and their families. Thus, the study aims to present the actual living conditions and needs of children with Ds and their families, with regard to the provision of social services.

To allow a cultural comparison with Australia one middle eastern country, Iran, has been selected¹. Overall, this study provides:

- a review of current literature and resources on Down syndrome;
- a review of current literature on the provision of social services for children with Ds and their families;
- a series of propositions indicating the types of intervention, which will improve the quality of life of children with Ds ; and
- strategies to improve current practices for children with Ds in both Iran and Australia.

At the outset it should be noted that since there is only one Down syndrome association for children with Ds in Iran², it is anticipated that through national and international cooperation, children with Ds will have better access to social service

programs worldwide. This research will make a substantial contribution towards this goal.

1.8 Thesis Outline

In this chapter, the problem has been introduced. The problem relates to the living conditions of children with Ds and their families with regard to provision of social services. The theory of normalisation and the social perspective of quality of life have been introduced as the theoretical frameworks of the study. Key terms: disability, Down syndrome, and social services, used through out this thesis have been defined and discussed and the significance and contribution of the research, have been identified.

Chapter 2, literature review, consists of two parts. In part A the nature of Down syndrome and its physical and intellectual effects are discussed in light of recent research. In part B, the literature pertaining to social services is reviewed. Due to the particular role played by social workers in the life of children with Ds, their tasks are discussed, and various programs are examined followed by a discussion of provision of social services. Important factors impacting the life of a child with Ds are identified. A review of relevant literature includes recent discussion about the gap between parents' needs and professionals' understanding of the needs of parents

In chapter 3, the overarching conceptual orientation driving the study is presented including theoretical statements of 'normalisation' and 'quality of life' in the context of the issue of 'disability' as a socio-political construct.

In chapter 4, the research method is presented. The nature of the problem prompted a qualitative interpretive approach to the study through the development of case studies of children with Ds and their families. Case studies and survey research methods are discussed as well as the ways that data was collected in Tehran, Tasmania, and Mainland Australia. Ethical considerations, issues such as validity

and reliability are described. The process undertaken to analyse data is explained. The limitation of the study is presented.

In chapter 5, the findings from case studies, interviews in Iran and Tasmania as well as the findings from the survey on the Australian mainland are presented. Participants suggested a range of practical solutions in relation to their experiences of raising a child with Ds within society.

In chapter 6, the results of the analysis of the data are presented. Conclusions in relation to the stated aims of the study are presented and suggestions for further research are outlined.

Chapter 2.0

Literature Review

This chapter consists of two parts: Part A and Part B.

2.1 Part A: Down syndrome

Part A will discuss the literature in relation to the nature of Down syndrome. Down syndrome affects children physically and intellectually due to the extra number 21 chromosome, and literature reviewed about their physical, and health characteristics in the context of their living environment will lead the study to the role of parents, professionals, and society. This review includes:

- the type of treatment in the past and at the present;
- the effect and efficacy of early intervention programs during infancy, preschool and during elementary school; and
- the impact of parental involvement in early intervention programs.

Prof. Lejeune's speech at a conference, addressing the possibility of diminishing the deleterious effect of the extra number 21 chromosome is also presented.

2.2 What Is Down Syndrome?

Down syndrome is a congenital chromosome abnormality which affects the physical and intellectual ability of the child, therefore, a discussion of their physical and intellectual characteristics is necessary.

In 1866, John Langdon Haydon Down, described five classes of patients: Caucasian, Ethiopian, Malay, American, and Mongolian. Because he paid more attention to the class of Mongolian, this class later became known as Down's syndrome named after Dr Down. Although Lejeune and his colleagues discovered trisomy 21 in 1959, 'Down's syndrome' is the universally accepted term. Later, The

World Health Organisation suggested dropping the apostrophe 's', therefore 'Down syndrome' or briefly 'Ds' is the term accepted worldwide (Stratford, 1989).

The overall incidence of Down syndrome is one in 660 live births (Newton, 1992 p.34). This rate is universal and is not related to race, nationality, or socio-economic status. The comparison countries in which this study is based provides useful data. In Iran, this means that approximately 3, 400 children of 2, 244, 000 (UNICEF, 1996) born annually will have Ds. In Australia, this means that approximately 345 children of the 240, 000 born annually will be born with Ds.

Down syndrome results in a combination of developmentally slowing factors. There are 46 chromosomes, grouped in 23 pairs in each cell of the body, but children born with Ds have 47 chromosomes instead of 46 in each cell. A majority of these children, 94%, have three individual number 21 chromosomes instead of a pair, which is called trisomy. About 3% of children with Ds have the extra chromosome attached to another chromosome, usually to number 13, 14, or 15. This is called translocation. The remaining 3% of children with Ds have normal cells (46 chromosomes) but the majority of cells are trisomy. This is called trisomy/normal mosaicism (Dmitriev & Oelwein, 1988).

A brief historical examination of social attitudes and assessment of children with Ds based on Stratford's research enables a clearer understanding of Down syndrome. Stratford (1989, p.15) stated that a child with Ds was considered in Meso America "a supernatural one" in Olmec times (between 1500 BC and 300 AD). In the fourth and third centuries BC, the Greeks believed that people with a disability 'were not human', but Aristotle asserted that they were human. The social attitudes were still negative in the fifth century AD when the mother of a child with Ds 'was thought to be especially to blame'. In the European Middle Ages, people with a disability were under negative social pressure although the rich had an opportunity to protect their children with a disability, but about 100 years ago, in Punjab, people with a

disability were respected as 'Shah Daula's rats' and today in some parts of India, people with a disability "are venerated at the shrines" (p.17).

From the genetic and medical point of view, in the 1600s, there were theories about medical causes of Ds. For example, Willis, an English medical doctor, suggested that "something must have gone wrong in the parents' reproductive system" (p.40). This idea persevered during the eighteenth and nineteenth centuries. In 1838, Jean Etienne Esquirol, a French physician, described a person with Ds for the first time. In 1844, Chambers elaborated a degeneracy theory and attempted a classification in his book *The Vestiges of the Natural History of Creation*. In 1866, Langdon Down described five classes of patients, one as Mongolian based on appearance and physical characteristics. In 1932, Waardenburg suggested a duplication of chromosomes, and in 1952, a female researcher, Mittwoch, investigated the numbers of chromosomes in each cell and reported that the chromosomes were not distinct, which was very close to Lejeune's discovery of trisomy 21 in 1959. But it was still not clear which biological or physical process caused this disorder (Stratford, 1989). However, the discovery of trisomy 21 by Lejeune in 1959 identified Ds as having a genetic cause, which affects the physical and intellectual ability of the child.

2.3 Physical Characteristics

Children with Ds have physical features in common due to the extra chromosome number 21. Some physical characteristics of children with DS are:

- a smaller head than the head of a 'Not Diagnosed with Anything' child (NDA child);
- the back of the head of a child with Ds is a little flattened;
- the face is flat with a narrow nasal passages;
- the eyelids are narrow and a little slanted;
- the ears are small;

- some children keep their mouth open because the tongue sometimes protrudes; the neck is slightly broad;
- the hands and feet are somewhat small and stubby;
- there is a gap between the first and second toes;
- the fingers and toes look short;
- children with Ds may have flat feet, and poor muscle tone;
- dryness of the skin has been seen in some children with Ds; and
- in addition to chromosome abnormality, a child with Ds may have a range of the above mentioned physical features (Pueschel, 1993b; Stratford, 1989)

2.4 Health Characteristics

Children with Ds may have one or more health problems as follows:

2.4.1 Congenital heart disease

About 40 per cent of children with Ds suffer from congenital heart disease, and about 30 to 35 per cent of deaths in Down syndrome are due to congenital heart disease (Newton, 1992, p.70). Routine echo cardiography is recommended for all newborn children with Ds.

A recent study from British Columbia reviewed the life expectancy of 1,341 people with Ds, for those with congenital heart disease survival at age 5 was 62 per cent, to age 10 was 57 per cent, to age 20 was 53 per cent, and to 30 was 50 per cent. For those without congenital heart anomalies the corresponding figures [estimated] survival to age 5 in 87 per cent, to age 10 in 85 per cent, to age 20 in 82 per cent, and to age 30 in 79 per cent (p.118).

Children with a congenital heart disease have a lower chance to survive as they get older compared with children with Ds and without congenital heart anomalies.

2.4.2 Infection

Children with Ds usually have poor responses to infections. They may have respiratory, chest, or ear infections. Many children with Ds often have a continually runny nose as they pass from one cold to the next, especially in winter time .

2.4.3 Visual impairments

Children with Ds may have eye problems and need glasses. According to Stratford (1989, p.58), Gradiner, a British ophthalmologist, gave a figure exceeding 67 per cent of individuals with Down syndrome having defective vision. The defects are short sight, long sight, astigmatism, or convergent or divergent strabismus.

2.4.4 Hearing problems

Children with Ds may have hearing problems. The problem is usually in the middle ear, and medical treatment is in the form of drug therapy or surgery.

2.4.5 Thyroid gland dysfunction

Some children with Ds may have an increased amount of the thyroid hormone which is called hyperthyroidism, or a decreased thyroid hormone level which is called hypothyroidism (Pueschel, 1993b, p.82). However, Hypothyroidism is more common, and their thyroid function should be checked regularly in order to prevent additional brain damage.

2.4.6 Skeletal abnormalities

Children with Ds may have loose or double jointedness. They may have atlantoaxial instability which can be diagnosed by X ray. All children with Ds should have an X ray of the neck, especially before starting sport activities such as football, gymnastics, trampolining, horse-riding, or butterfly-stroke in swimming (Stratford, 1989, p.63).

These health problems are not all necessarily present in a child with Ds. The occurrence of these problems depends on the degree of disability which may be mild, moderate, or severe.

2.5 Treatment

Medical advances have led to better health care, pre-natal diagnosis, and most importantly, research in the field of Ds, and therefore children with Ds now live longer and are healthier than in the past (Pueschel, 1993b). One of the solutions to

minimise perceived adverse physical features of children with Ds has been plastic surgery. It was performed for the first time in Argentina in the mid 1970s (Stratford, 1989, p.78). As children with DS usually have a flat nasal bridge and epicanthal folds, in plastic surgery an "implant to the nose creates the illusion of more normal eye position and improves profile, along with implant to chin and defatting of neck" (Dmitriev & Oelwein, 1988, p.64). Since there is a notion that children with Ds do not have to go through facial plastic surgery in order to look normal to the society, this surgery has been a controversial issue. In contrast, tongue reduction, when a child with Ds has an over-enlarged tongue, improves the condition of the child and makes the child with Ds able to close his/her mouth (Stratford, 1989, p.79).

Vitamins such as B6 and minerals have been used as a treatment. For example, Henry Turkel (Pueschel, 1993b, p.89) treated children with Ds with a combination of minerals, vitamins, enzymes, and hormones, referred to as the U-series, in the 1960s. While some studies report physical and intellectual improvement of children with Ds who used U-series, Pueschel (p.90) argues that "no drug treatment to date has been found effective for children with Down syndrome". Studies of a recent drug treatment known as MSB will be discussed in part B of this chapter .

2.5.1 Cell therapy

The Swiss surgeon, Niehans, used cell therapy for the first time in the 1930s for children with Ds. In this treatment children with Ds receive injections of cells from the organs of unborn donor animals, sheep or cattle. The success claimed for cell therapy is based upon an alleged affinity that exists between the cells of a particular organ from the embryonic donor animal and the corresponding organ of the patient (Dmitriev & Oelwein, 1988, p.86).

Van den Berghe (Stratford, 1989, p. 87), the Belgian geneticist, noted that cell therapy did not have any effect on the physical or intellectual improvement of children with Ds. Foreman and Ward in 1987 (Newton, 1992, p.146) at Macquarie University in Australia, identified 57 families receiving cell therapy. Of these 57

families, 53 were studied. The results indicated that there was no evidence for the effectiveness of cell therapy on appearance or developmental quotients of children with Ds. In spite of the lack of scientific evidence to support vitamin therapy and cell therapy, some parents who have a child with Ds continue the treatment for their children because they believe in these therapies.

Health problems of children with Ds such as visual impairment, hearing problems, thyroid dysfunction, heart disease, and over-enlarged tongue can be prevented through medical treatments. But the problem is that parents may not be aware of physical and health characteristics of their child with Ds. Thus, many children with Ds do not have the opportunity for improvement until they enter school and teachers recognise their problem. A preventive medicine checklist by the National Down Syndrome Congress (1994-95) provides an appropriate examination schedule suggested from the neonatal period to adulthood. Each assessment consists of personal history, suggested physical examination, lab tests, consultation, and recommendations (Appendix A).

2.5.2 Dolphin human therapy³

Dolphin human therapy is a program conducted by Nathahan (Email, 1995a) in Miami, Florida for adults and children with a disability. The theory behind dolphin therapy is that children or adults will increase attention as a result of a desire to interact with dolphins. Thus, the general purpose of the program is motivational, although specific objectives for each child may include behaviours related to speech, language, and gross or fine motor development.

2.6 Early Intervention

Children with Ds have physical and intellectual limitations which can be modified by early intervention training. Early intervention is based on the assumption that significant improvement can be achieved by ordered stimulation (Newton, 1992). According to Pieterse and Bochner (1990, p.569), 'early' refers to "an

intervention service that is implemented as soon as a developmental risk is identified; 'intervention' refers to purposeful educational or therapeutic services designed to alleviate or remedy the 'at risk' factors". Physical limitation is partly due to muscle weakness or hypotonia, therefore the learning process should be started from birth by stimulating the sensorimotor of the child with Ds.

Different approaches have been used in order to classify the types of early intervention programs. The most frequently used approach for classification is acquired from the theories of child development and learning that underlie the teaching programs objectives and procedures. Pieterse and Bochner (1990) reviewed early intervention programs which can be classified into four main types:

- 1- *biological* based on the assertion that developmental processes are inborn and the pattern of early development is determined primarily by maturation (Bower, 1979; Lenneberg, 1967),
- 2- *behavioural* using procedures derived from Skinner's (1957) stimulus response learning model,
- 3- *cognitive* based on Piaget's (1953) stages model of early learning, and
- 4- *interaction* incorporating the dyadic model of learning described by Bruner (1978), Vygotsky (1962) and others (p.572).

However, current programs in early intervention emphasise factors such as family, including parents and siblings, as well as the child and teaching situation for improvement of the child.

2.6.1 Intelligence Quotient (IQ)

An IQ is "a measure of an individual's performance on an intelligence test relative to his or her age group" (Casey, 1994, p.61). Intellectual limitations are partly due to low intelligence. Intelligence tests became popular in the form of intelligence quotient (IQ) test. One of the ways for early identification of children with a disability has been based on intelligence quotients (IQ) which is a very controversial issue. The following discussion suggests that IQ is not recommended for identifying the intellectual degree of children with a disability.

Historically, the first IQ was produced by Fitzherbert in 1534 (Stratford, 1989, p.39). Since then many different IQ tests have been presented including the Binet and the Wechsler tests to identify children with an intellectual disability (Casey, 1994). A review of literature suggests that IQ testing is not recommended for classification purposes. The viewpoints of Ashman (1998), Brown (1988), Casey (1994), and Cunningham and Sloper (1983) in relation to IQ have been summarised as follows:

- IQ scores and divisions are not absolute ...,
- IQ can change ...,
- IQ does not measure the mental ability a child was born with ...,
- A good environment can improve IQ,
- Many people with a disability have found IQ and aetiology labels offensive,
- In fact, IQ tells little about how a person will deal with daily problems,
- knowledge of an IQ or an IQ test profile alone will not help a teacher develop teaching programs for children with a learning difficulty or make curriculum decisions,
- IQ test does not validly assess ability,
- IQ test is not appropriate for children in another culture,
- No intelligence tests can be totally culture-free,
- IQ scores are not immutable, scores are likely to fluctuate from day to day, and
- IQ scores are not precise. Some teachers and parents mistakenly believe that an IQ score is as precise a measurement as one measuring height or weight.

As a consequence of the reaction against using IQ in identifying the intellectual degree of children with a disability, "there has been an increasing reluctance on the part of psychologists and school guidance staff to administer intelligence tests" (Ashman, 1998, p.423). Moreover, Buttler (1990) asserted that since 1978, with emphasis on the integration of children with a disability into regular school, IQ testing has largely been rejected for classification purposes throughout Australia.

"Feuerstion (Pueschel, 1993b, p.104) has stated in numerous publications that intelligence can be improved by intervention and mediation, in which the adult intervenes between the child and the environment" . Identification of early intervention programs to make improvement is the preferred method.

2.6.2 Infancy

During infancy, visual stimulation such as colourful toys, auditory stimulation such as singing with varying rhythm, and tactile stimulation such as touching helps the child to improve the level of performance and competence (Zaumer, 1993). The philosophy of early intervention programs is partly based on a Piagetian model of development. Piaget (in Tingey, 1988) suggested that early learning is always sensory or experimental learning. According to learning theorists, learning is "partly related to the physiological capabilities of the learner" (Tingey, 1988, p.148). Since the physical and intellectual growth of the child with Ds is slower than the NDA child, their developmental accomplishments are slower too, as Table 2.1 indicates. However, it is important to note that children with Ds can make improvement in motor development through early intervention programs and decline the growth delay.

Table 2.1: Developmental milestones in children

	Children with DS		'Normal' Children	
	Average	Range	Average	Range
	(months)	(months)	(months)	(months)
Smiling	2	1 1/2 - 3	1	1/2 - 3
Rolling over	6	2 - 12	5	2 - 10
Sitting	9	6 - 18	7	5 - 9
Crawling	11	7 - 21	8	6 - 11
Creeping	13	8 - 25	10	7 - 13

Standing	10	10 -32	11	8 -16
Walking	20	12 -45	13	8 -18
Talking, words	14	9 -30	10	6 -14
Talking, sentences	24	18 -46	21	14 -32

Source : Canning and Pueschel (in Pueschel, 1993 p.97)

2.6.3 Preschool

In preschool years (3-5 years) some children with Ds benefit from early intervention and learn through activities in preschool programs. Maria Montessori, from 1870 to 1952, the first female Italian doctor, provided a school for children with a disability and emphasised muscle and sensory training to enable children to learn better (Casey, 1994, p.9). In Australia, children at the age of three are offered places at preschool, but there are children of that age who benefit from an intensive period of early intervention such as speech therapy. The only way that parents can get this for their children is to use a private program. This means that children whose parents cannot afford a private program are being disadvantaged by a lack of funding for speech therapy (Email, 1995b).

In the United States (US), the recommended intervention has been to place children with Ds in institutions, and during the 1950s placement of infants with Ds in institutions increased. During the 1960s, parents tended to train their children with Ds in the home, and home intervention programs were developed which were called *infant stimulation programs* . These programs emphasised visual, auditory, and tactile stimulation (Tingey, 1988, p.137).

The question of early intervention in the lives of preschool children raises issues such as the nature of professionalism and the role of professionals. In fact, the basis of professional judgment on how to define a child as 'in need', or 'special' is a critical issue. In general, people with a disability are perceived as being dependent

on experts, and professionals have the authority to make decisions affecting the lives of people with a disability.

2.6.4 Elementary School

During elementary school, children gain an educational experience, the development of social relationships, and are taught reading and writing skills. In some countries such as the US, where federal law PL 94-142, mandates education of all children with handicaps, children with Ds have better opportunities for education and benefit of a range of services such as occupational and physical therapy (Neufeld, 1991, p.37). However, throughout the world the philosophy often differs with the reality. For example, according to UNICEF, only 1% of children with disabilities attend school, and problems such as transportation is a major factor not being able to attend school. Besides, there is a belief that a child with a disability can not benefit from the education (UNICEF, 1995).

2.6.5 Efficacy of Early Intervention

Researchers at the Early Intervention Research Institute at Utah State University made an effort to "collect all efficacy studies on Down syndrome as part of a larger integrative review of early intervention research" (Casto, 1988, p.138). The data from 16 studies, conducted from 1964 to 1984, were summarised. These studies were reported in medical, psychological and educational journals, and governmental reports (p.139). The result of this review indicated that early intervention programs produce modest developmental gains in infants and young children with Down syndrome.

According to Spiker and Hopmann (1997), early intervention in Australia represents an important area of development which has contributed substantially to current moves towards the integration of children with Ds into regular preschool and schools.

Indeed, many of the earliest studies of children with Ds claimed positive effects of early intervention by analyses indicating slower declines in developmental quotient (DQ) or (IQ) for early intervention participants

(p.274).

In England, *The Children Act* 1988 was the most comprehensive legislation at that time relating to the care and protection of children. Although much of the act is about child protection, consideration is also given to children with disabilities. In spite of this protection and consideration there have been doctors who sympathised with what they thought were parents' desires and allowed children with Ds to die. Silverman (Newton, 1992) studied the attitudes of doctors, working in a British paediatric cardiology clinic in the early 1980s. The results indicated that the physician made the assumption that a child with Ds could not be well and therefore did not bother to ask parents. Many doctors perceived that a "child who is not altogether whole or is imperfect may turn out to be imperfectable" (Newton, 1992, p.141). Likewise, doctors tended not to intervene in congenital heart disease, therefore had "mixed in their minds the concept of health and handicap" (p.142).

The majority of studies considering the results of early intervention programs have been reported from North America, Britain, and Australia. Only a few third world countries (TWC) have made efforts to form policies for assessment, referral and early intervention. It is generally believed that early intervention can be effective from the birth of the child, therefore parents should be informed of early information programs as soon as possible.

2.6.6 Parental Involvement

Parents can have an important role in early intervention. Hornby (1991) discussed various aspects of involvement in early intervention which include the problem of adaptation to the disability, the early needs of parents, and models of family functioning. In describing various reactions of mothers, he put mothers' reactions in the following order in which they are typically experienced.

1. Shock - parents feel confusion and helplessness. Hornby (1991) stated that parents "were unable to take in much of what they were told at this time" (p.207).

2. Denial - parents deny the reality of the situation which is a temporary coping strategy.
3. Anger - parents may look for a cause of the disability, or they may blame themselves for giving birth to a child with a disability, or blame hospital staff.
4. Sadness - parents may feel depressed for a period of time.
5. Detachment - parents accept the reality of the disability, but they are careless to their surroundings.
6. Reorganisation - at this stage, parents are realistic and consider the reality of the disability.
7. Adaptation - parents come to the situation of accepting their child and adapt themselves to their new situation as parents of a child with a disability.

It can be concluded from Hornby's discussion that it is very important how and what parents are told when they receive the news that their child has a disability. At the birth of their child, parents expect to hear that they have a healthy child. This gives them lots of hope for the future of their child and brings dignity to their family. When parents hear they have a child with a disability rather than having a healthy child, they will not feel happy.

To emphasis parents' roles and the impact on research and practice with families of children with special needs three models are discussed. These are

- the transactional model,
- the ecological model, and
- family system theory (p.212).

In the transactional model, it is believed that families both affect and are affected by their child with a disability. For example, a child will affect parents as the child passes through different developmental stages. Likewise, children are affected by family characteristics such as age, job and the level of parents' education.

In the ecological model, the environment influences behaviour and development. Thus, factors such as the education system, voluntary agencies and economic, and political beliefs are important for the development and behaviour of a child with a disability.

In the family systems theory, "the behaviour of family members is considered to be a function of the system of which they are a part" (p.213). If the family system changes, the behaviour of members of the family will change. Likewise, a change in an individual's behaviour will lead to a change in the family system.

Thus, parents can play an important role in the family system as well as the environmental factors. To justify the above components for families with a child with Ds, it appears from the literature that parents feel helpless and may blame themselves, and factors such as education system and political beliefs are important for the improvement of the child.

Parents also have strengths due to having a child with Ds and have valuable information about their child's strengths and weaknesses. This information can help professionals gain an understanding of family resources and interaction.

Some parents pursue higher education about Down syndrome as professionals. In fact, part of today's life improvement of some children with Ds is due to either parents being professionals or becoming professionals after the birth of their child with Ds.

In Western countries, institutions were considered as the solution to the problem of disability. This practice was especially common in towns because institutions were built in towns and institutionalisation began with children in towns. The philosophy behind institutionalisation was that a person with a disability would have a negative effect on the life of other family members and should be excluded from the lives of normal people. It was very common for professionals to advise a mother of a child with Ds to leave her child in the hospital. The child was later institutionalised for the rest of his/her life. Although the approach to the care

of children with a disability has been changing towards de-institutionalisation, and concepts of integration and normalisation have been emphasised, this advice was common among professionals in some countries such as Australia in the past. Beliefs and values in each society are important issues in forming attitudes toward disability.

2.7 Down Syndrome Medical Research

Professor Jerome Lejeune, Professor of Genetics at the Rene Descartes University in France, discovered the extra chromosome in trisomy 21 in 1959 and devoted his life to search for a treatment until his death in 1994. He did not support the use of genetic knowledge to approve abortion, and two years before his death, at a conference in London he discussed how the intellectual damage resulting from this extra chromosome can be identified, and how it may be possible to diminish the deleterious effect of the extra chromosome. The following is part of his address at the conference:

It is now more than 30 years ago that I saw the extra tiny chromosome for the first time. If I did a rough conclusion, I would say that, then, for a baby conceived an extra chromosome of the number 21, the probability of reaching 10 years of age was a little greater than it is today, because today some of them will be killed by abortion or by deliberate neglect at birth if they have some abnormality in the gut or the heart ... I am afraid that infanticide is increasing where babies are affected by any kind of abnormality.

Our once civilised countries are becoming harder and harder when it comes to respecting their own handicapped members... A method which is already used is to study the chromosomal abnormalities and try to analyse the few gens we detect on chromosome 21 (Lejeune, 1994, p.6).

Lejeune's colleagues, including Dr Marie Peeters(1994, p.7), continued his research, and "published a study which demonstrates the beneficial effects of folic acid and methionine on the IQ of children with Ds aged less than five years". Medical research can influence intellectual and physical improvement of children with Ds.

2.8 Summary of Part A

The purpose of this part was to discuss the literature in relation to the nature of Down syndrome and its effects. Down syndrome is a congenital chromosome abnormality which affects physical and intellectual ability of the child. Since Down syndrome affects children's physical and intellectual abilities, their physical and intellectual characteristics were discussed. The main points emerging from this review of literature on Ds include:

- Parental issues: Parents feel helpless and depressed. They may blame themselves. Parents can play an important role for the improvement of the child.
- Early intervention programs: these produce modest developmental gains in infants and young children with Ds, and parents can have an important role in early intervention. Although IQ testing has been common in the past it is not recommended today for classification purposes.
- Professionals' role: professionals' role, in particular in medical research, is very important. For example, medical research suggests that there are three possible methods in order to unravel the genetic inheritance carried by chromosome 21. Today, babies with Ds can be protected from an accelerated regression and severe retardation if they are checked when they are young -from birth to five years- in order to benefit medical programs.

2.9 Part B: Social Services

The review of the literature in part A suggested that early intervention programs can be effective, and parents can have an important role in early intervention.

The focus of this part is on social services. Since social workers have an important role as providers of social services, the field of social work and the task of social workers are defined. This review includes:

- the four ways in which disability is understood in social work practice (the illness model, the minority status model, the social barriers model, the system case manager model);
- welfare programs and the provision of social services;
- three factors: family, society, and services which affect the life of children with Ds;
- the gap between what parents need and what professionals think parents need.

2.10 Social Work

Due to the key role played by social workers as providers of social services to children with a disability, the field of social work and tasks of social workers are defined. The profession of social work began about 100 years ago in the US with the aim of helping people and developing services to meet their needs. Today, social workers aim to solve people's problems and "enhance the quality of life of all people" (Morales & Sheafor, 1992, p.2) through presenting access to social services. Thus, social workers practice

within the context of the entire social welfare institution and must seek to make the institution more responsive to human needs ...The social welfare institution finds expression in the form of laws, policies, services, human service agencies, volunteers, and the variety of professions and other occupational groups that make it possible to help people meet their needs (pp.91-98).

Two key periods of time are considered in the history of the United States, which influenced the development of the social welfare institution internationally: Colonial times to the Great Depression, and The Great Depression to the Present.

2.10.1 Colonial times to the Great Depression

During this time, the family in Western societies was a strong institution, each member in the family had defined roles, and even those with a disability could be contributing productive members of the family. The family and the market system were responsible for human needs, therefore the society rarely needed to take

responsibility in solving problems and when it did, the church usually took on that role. Thus, the family, the church, and the market economy were the social institutions. The movement from an agricultural society to an industrial society in the 1800s and 1900s, made society more responsible for unmet human needs.

2.10.2 Great Depression to the Present

Many services were developed, through philanthropic activities, but the Great Depression of the 1930s resulted in an increase in numbers of needy people. After World War II, social welfare institutions were expanded. Although in the 1960s, after the 'Human Right Revolution' many people including people with a disability had a voice, children with a disability did not have a desired living situation.

Through history, people with a disability have been viewed as special, different, pitiful, or as a burden on society. Each of these views has led to a philosophy about disability. Quinn (1995) suggested that understanding these views would help social workers for future planning. Quinn discussed four models; the illness model, the minority status model, the social barriers model, and the disability systems case manager model (p.72).

The illness model regards a person with a disability as being physically sick. This is the same perspective as medical discourses argued by Fulcher (1988). In the minority status model, the socio-political environment is believed to be the main problem. This model is similar to the social construction of disability argued by Oliver (1986), and has led to the establishment of the disability rights movement. The Independent Living Center is one of the outcomes of this model which began in Berkeley in the 1960s and provides advocacy, resources and referrals (Quinn, 1995, p.73). In the social barriers model, social and environmental restrictions are believed to be the main cause of the problem and the attitudes toward disability should be changed, thus this model is similar to the social model of disability discussed in chapter 1 section 1.5.

Social work has adopted a model called the disability system case manager model which promotes the belief that the environment and the system should concentrate on responding to the needs of people with a disability. The disability system case manager serves as an advocate between service providers, staff who present services, and consumers, that is, people with a disability. The tasks of the case manager comprise: "studying and understanding rules and regulations; coordinating between and among various services; advocating for change; and speaking with and for [people with a disability]" (Quinn, 1995, p.77). Consideration of the literature in relation to the needs of people with a disability provides a useful framework.

2.11 Welfare Programs

What are the main welfare programs, who is eligible to receive them and What proportion has been allocated to people with a disability? According to Barry (1990), the first aim of the welfare philosophers was redistributive: the "common provision of education, health services, unemployment insurance, and so on, would itself be a mechanism both for the achievement of equality and the relief of deprivation" because the social philosophy of welfare has been related with equality (p.101).

The Australian welfare state developed at the beginning of the twentieth century. Nearly 60 per cent of the Commonwealth budget goes on social expenditures with "over 30 per cent spent on social security and welfare, 15 per cent on health, and less than 10 per cent on education" (Healy, 1999, P.53). There remains continuing demands on the welfare system. This is because the population of the elderly is increasing, there are more students leaving school who are unable to find employment, and more women are seeking jobs. The question is who is eligible for assistance and who should be excluded.

A chronological review of the development of welfare programs indicates that major programs of welfare states were established in the decades after World War II. However, the basic idea of the welfare state formed between 1870 - 1920. For instance, Germany chose a system of compulsory insurance between 1882-1889 to protect its citizens against accidents and illness. Ten years later, in 1898, New Zealand established a similar plan. In 1900, the Australian states of Victoria and New South Wales adopted 'age-pension schemes' (James, 1992).

Although the chronological development of welfare state programs goes back more than a century, "as new social and economic limits are perceived, as new value system arise, as consumer expectations grow and as the independence of national economics decline, there will be great and inevitable changes in welfare system" (Healy, 1999, p.151).

The important issue is that other main welfare state programs in industrial and developing countries such as education, health, and welfare services do not cover all population groups, especially groups that are called 'special populations'.

2.12 The Provision of Social Services

In Australia, in the late 1800s, voluntary organisations were established to protect and care for the poor and people with a disability. In other words, people with disabilities including people with Down syndrome, were institutionalised and segregated from the rest of the community. Historically, non - governmental agencies had an important role to fund services for people with disabilities.

In 1986, the *Disability Services Act* was passed. One of the objects of this Act is "to replace provisions of the *Handicapped Persons Assistance Act 1974*, and section VIII of the *Social Security Act 1947*" (No. 129 of *Disability Services Act 1986*). In 1992, the *Commonwealth Disability Discrimination Act* was passed to protect the rights of people with a disability. It should be stressed that this model is the norm in the situation in Western countries. However, people with disabilities in developing countries

usually do not have their needs met as do those in the West. Children with disabilities are unevenly distributed worldwide and 80% of them live in poorer countries with poorer medical and social rehabilitation resources (UNICEF, 1995). If the issue of disability in both industrialised and developing countries is examined, it is clear that the majority of people with disabilities are living in developing countries and are deprived of a basic standard of life. According to WHO "less than 3% of adults or children with disabilities receive rehabilitation of any kind" (UNICEF, 1995). The main reason is due to the lack of a supportive system and appropriate environment for people with a disability.

By way of comparison, In Iran during 500 B.C. there existed government centres whose purpose was to assist people with particular problems. In later times religious and voluntary organisations including self help groups provided limited services. A new welfare system was developed in the 1920s and by the 1930s public agencies having the responsibility to provide problem-based assistance utilising social workers, had been developed. After the Islamic Revolution, all public and voluntary agencies were formed into the Welfare Organisation of Iran. Meanwhile in recent years, many non profit agencies and religious organisations now provide services such as family support, medical and marriage financial aid and, homes for the aged.

A lack of appropriate preventive programs and primary health care may result in a low quality of life of children. According to UNICEF "90% of disabilities are mild to moderate; if caught early, they can be handled generally and with minimal resources" (UNICEF, 1995). The position of children with a disability is not desirable because resources are limited. Carney (1993) argued that children with disabilities encounter four main problems:

- inadequate access to resources;
- a lack of sufficient public advocacy for their position in the face of professional or community insensitivity to the measure of those needs;

- too compromised a view of their entitlements to respect for their human right, and
- a lack of development of concrete measures to secure greater compliance with human rights benchmark (p.18).

In addition to the above mentioned problem, there is still a need for adequate data to know children's needs and wants. Moreover, parents do not have access to services, as Cox (1989 in Carney, 1993) observed:

Significant advances have been made in recent years to move away from the medical model, hospital based service to a more comfortable, community based agency where the focus is on the needs of the child. But parents still need support and help in finding agencies with the services their child may need (p.19).

In Australia, services for children with disabilities are largely provided by the residual welfare system. In this system, the family and the market are supposed to meet individual needs, and only if they have failed, does the social welfare system take responsibility temporarily (Cant & Hand, 1994).

Despite the range of services provided for children with disabilities by the state in Western countries, these are considerable when compared to the situation in developing countries. With the enactment of de-institutionalisation, the emphasis of care and the provision of needs for children with disabilities is family- based, supported by services provided by the state. However, policy decisions and funding inequities result in the failure to meet the state's objectives for people with disabilities. In their article "Who cares for these children?", Cant and Hand (1994) reviewed recent Australian commonwealth and state documents dealing with the provision of services for children with developmental disabilities, and highlight issues such as the difference between payments made to parents caring for a child with a disability at home and those paid to people fostering a child with a disability in the state of NSW. They note that if natural parents take care of their own child with a disability, a Child Disability Allowance of \$68.30 is paid per fortnight, and if the child is fostered, the amount of \$194.70 is paid to the foster family per fortnight.

This amount can be increased to a maximum of \$580 per fortnight for a child with a severe disability. Cant and Hand concluded that: "the contrast between the payments for care made to foster families and those to other families underlines the reluctance of the state to acknowledge collective responsibility for all children with significant disabilities" (p.17).

It goes without saying that children with a disability should have the same rights as other children to live in a family environment including "hugging, individual care, sitting on Mom or Dad's lap, playing, [and] laughing" (Hegarty, 1993, p.240). With regard to the contrast between the payments, some foster families may have materialistic motivations. Even though a family does not have a materialistic motivation, the loss of love and affection by the natural parents may only be partially satisfied by foster parents. Money cannot buy love and affection, and the contrast between the payments does not fulfil the purpose of care by a family in order for the needs of children with disabilities to be answered.

There is no doubt that the improvement of the living situation of children with a disability depends considerably on legislation such as in the US, in 1975, the *All Handicapped Children's Act* (PL94-142). this was passed and free education for all children with special needs became compulsory. Clearly, to pass legislation for the protection of people with a disability does not necessarily mean that people would have the type of support that they expect. Although in Australia, social services are the constitutional responsibilities of the state government, Healy (1999) concluded that

the Australian welfare state can no longer rely upon a high employment economy. Its residual welfare services, which were originally intended for the few, may be needed by many more, given an ageing and more disadvantaged population; while voters accustomed to low taxes will be reluctant to pay more to fund an equitable welfare state (p.150).

As a summary, children with disabilities encounter problems including inadequate access to resources and parents still need support and help to find services for their children.

2.13 Three Main Factors Influencing Children With Ds

Three factors (family, services, society) have a crucial influence on the life of a child with Ds.

2.13.1 Family

The family is the first social institution in which the child forms his/her personality, and is prepared for further education in society. Siblings, the culture, class and socio economic status of the family, can positively or adversely affect the life of the child. In relation to family, three models were discussed in part A and it was suggested that the family can affect the life of a child with Ds.

Results from the following study indicated that some parents are misinformed by professionals when seeking information about Down syndrome. Shepperdson (1988) carried out research in Great Britain in 1972 and 1981, which consisted of a two-part study of children with DS and their families. The study concentrated on the differences between those families who have a child with Ds, and families who have either a child without a disability or a child with another type of disability instead of emphasising the differences and similarities between these groups of children.

Some of the aims of the research were:

- to depict the variations in how families cope, emotionally and practically with the fact of having a child with Ds, and
- to ascertain to what extent families with a child with Ds receive similar services.

In the first part of the study, in 1972, 36 children, at the beginning of the school years, were studied, and in 1981, 33 of them, at the end of school years, were studied. Some of the results indicated that "how a parent is told about her child's handicap

has been a common subject of complaint ... parents wish to be told as soon as there are anxieties about their baby..." (p.124). When parents were told about the child, "they were not given a great deal of advice at the same time... and sometimes the advice was more pessimistic and parents were told 'He will never walk or talk'..." (p.131). In summary, parents needed to have more information in order to know the seriousness of disability of their child.

2.13.2 Social Services

Basic social services for children with Ds are early intervention, educational and health services.

2.13.2.1 Early Intervention

The physical and intellectual limitations of a child with Ds can be decreased by early intervention programs. Early intervention strategies are used to increase the child's interest, attention, and skills in general. There is evidence that these programs are effective in facilitating the development of infants with Ds (Dmitriev & Oelwain 1988; Hanson 1987). Pueschel (1993b) believed that specific strategies should be used for the improvement of the child's interest, attention, and skill level. Early intervention first began in the US in the late 1950s and early 1960s with the goal of improving mental development. Pueschel (1993b) stressed that early intervention can be very effective for infants' sensorimotor and social development. Oral exploration such as exploration by mouth, visual stimulation from birth such as using colourful objects above the crib, and auditory stimulation such as talking and singing to the child augment the child's attention.

Studies of early intervention for children with Ds indicated that early intervention helps to provide social and emotional support as well as informational support to the family (Spiker & Hopmann, 1997). Ashman (1998) stated that early intervention for children with special needs is effective in:

- producing gains in physical development, cognitive development, language and speech development, social competence and self help skills;

- preventing the development of secondary handicapping conditions;
- reducing family stress and helping parents and support the development of a young child with disabilities;
- reducing the likelihood of social dependence and institutionalisation;
- reducing the need for special education services or placement in special classrooms once the child reaches school .

For students with a mild intellectual disability, the goals of early education are:

- receptive and expressive language skills,
- gross and fine motor skills through ball games and other play activities,
- self-help skills such as dressing and toileting,
- pre-help skills such as holding and using a crayon, pencil or scissors, and
- social skills such as cooperative play, sharing and taking turns (p.444).

Early intervention for children with Ds is effective in reducing the need for special services and developing skills such as social skills and self-help skills toward having a normal life as much as possible.

2.13.2.2 Education

The purpose of education is to prepare "individuals to function effectively and successfully as adults" (Puschel, 1993b, p.179). According to Lawrence (1998) since 1994, people with a disability have been designated by the Australian National Training Authority as a disadvantaged target group, or those under-represented in vocational education and training.

Effective guidance encourages children to take an active role in their own learning. Mothers have the primary role to motivate their child's learning because mothers spend the most time with their children before preschool education starts.

The first school in the history of special education was opened by Edouard Seguin in 1839 who proved attention and care will improve the situation of children with a disability. Casey (1994, p.11) discussed that a number of authors (Dunn, 1973, Gearheart et al., 1988) have identified three stages of development of educational services for students with a disability in the twentieth century in Western countries:

Up to the 1920s : Era of neglect

During this time, children with a disability had minimum access to provisions, and only those with severe disabilities were institutionalised.

1920s- 1960s : Era of segregation

During this time, social attitudes towards children with a disability improved, and special schools and classes were emphasised.

1960s - 1990s: Era of integration

The theory of normalisation prevailed with the aim of a normal life style for children with a disability, and they were allowed to study in regular schools.

In Australia, the first school for children with a physical disability was established during the 1860s, while children with an intellectual disability did not receive special education until 1930s (Casey, 1994, p.13). The first school for children with a hearing disability was established in 1880 in Sydney (Ashman, 1998).

Although the *Commonwealth Disability Discrimination Act* of 1992 approved integration of students with an intellectual disability into regular schools, literature indicates that there are still children with Ds who are segregated from society.

By way of comparison, Iran, the first school for children with a hearing disability was established in 1925. The first center for children with intellectual disabilities was established during the late 1950s (Sharifzadeh, 1992, p.32). In 1969, an exceptional school was established for children with an intellectual disability (Welfare Organisation of Iran, 1995). Meanwhile, students who fail in regular school are referred to exceptional schools. Exceptional schools, contain students with mild or moderate intellectual disabilities and students with behavioural difficulties, whereas the power of imitation, supports the idea that children with Ds should not be mixed with children who have behavioural problems.

Integration in the current education system of Iran is not possible because there is a national standard minimum educational attainment and therefore children who fall within the categories mentioned above usually fail in this system. While

research has suggested that if people, including children with intellectual disabilities, are given the opportunity, a majority of them "are able to learn even complex skills and can do so throughout their lives" (Conway & Gow, 1990, p.336). A survey of special education policies conducted by UNESCO in 1986-87 illustrated that of fifty eight countries surveyed, many emphasised that the aim of schooling is a stage in the preparation for adult life. Only Ireland "had an explicit objective that children with disabilities should lead full lives as children" (Hegarty, 1993, p.242).

The following are what parents expect of their children with DS after completing their education (Pueschel, 1993b):

1. To be able to interact effectively with persons who do not have disabilities as well as with those who have handicaps.
2. To be able to work in the same environment as those without disabilities.
3. To be welcomed and to participate with comfort and confidence at facilities and activities frequented by those without handicaps.
4. To live in housing of their choice that is within their economic means.
5. To be happy (p.180).

Therefore, the emphasis within education should not only be on gaining skills in reading, writing, and arithmetic, but also on being prepared for the next stage of life. For students to have a high quality of schooling, all should feel that school is a safe place for friendship, where they have physical access throughout the school and are respected by staff and other students. However, schools vary according to their geographical setting (rural, or urban), size, available facilities, and most importantly, in form of education system and the culture. For example, unlike the Australian education system, the Iranian education system is based on pass and fail, therefore only those students who pass successfully complete their primary education. In addition, Iranian students are supposed to learn many more subjective concepts with an emphasis on practice writing. Moreover, students, with or without a disability at primary school have considerable homework after school which does not leave enough time for them to have leisure time at home. Whereas according to Ashman

(1998) leisure and recreation activities are of importance in the education of students with an intellectual disability.

As Iranian students pursue further education and continue in high school they have to allocate most of their time to studying scientific concepts which they may never use in adult life. Clearly, many students fail at primary and high school, and students with a disability do not have a place among these students. However the study by Macy and Carter (in Casey, 1994, p.24) supported "the notion of improved performance of mildly retarded children in the normal classroom settings".

In contrast,

In 1986, Congress of the United States passed Public Law 99-457, the Infant, Toddler and Preschool amendments to the *Education of All Handicapped Children Act* of 1975, now known as the *Individual with Disabilities Education Act 1986* (IDEA), providing United States' citizens the opportunity to create the assurance of an optimal QOL for youngest children at risk of developmental delays or with disabilities and their families (Reif, 1993, p.235).

In the US, children with an intellectual disability may benefit from an extension education until the age of 22. After completing high school, "the state division of Rehabilitation and/or Division of Mental Retardation has a responsibility to guide young people with handicaps towards educational and learning opportunities suited to their potential" (Murphy, 1993, p.26).

There are discussions on age categories for children with Ds with regard to their developmental stage for receiving social services. In the US, federal law categorises by age; from birth to three, three to five, and school age to 22 or graduation from high school (Email, 1995c). On the other hand, part of the law in the US

which requires educational services for disabled and challenged individuals stipulates that the service be appropriate to the child. This is interpreted to the individual level, rather than categories (Email, 1995d).

With regard to education, although the situation of children with disabilities has been changed from minimum access to provision for integration in regular schools, parents expect their children with Ds to learn reading, writing, and arithmetic as well as being prepared for future work.

2.13.2.3 Health

Children with Ds received little health care in the past, and had limited opportunities for physical activity, whereas today these children, particularly in industrialised countries, have more choices in health care programs (Pueschel, 1993b). For example the preventive medicine checklist by National Down Syndrome Congress assists parents and professionals in assuring that appropriate, quality health care is provided to all people including children with Ds (Appendix A).

In 1964, a variety of medications including vitamins, enzymes, and minerals were used as treatment for children with Ds and indicated improvement in children. In 1981, it was reported that eleven vitamins and eight minerals were given to a number of children with Ds for a period of four to eight months, which resulted in three out of four children with Ds showing physical improvement of IQ (Pueschel, 1993b). Unlike Smith, a leading authority in the field of Ds, who does not consider nutritional intervention to be effective for improving intelligence (Stratford, 1989), there is evidence that vitamins play an important role in the improvement of children with Ds. Many parents add piracetam to the vitamins. While this is a controversial issue, those parents who used piracetam for their children reported a positive change in the physical and intellectual abilities of their child with Ds (Email, 1995e).

The progress of children who use vitamin supplementation, folic acid, and MSB⁴ and those who use NutriVene D supplements⁵ has been discussed by parents and professionals. There has been no scientific support for using this drug, but support is based on mothers' observations of their children. Denholm (1991) stated during planning stages of the National Conference on Down syndrome, preparing

for the year 2000, held in Victoria in 1989, the expressed need was to have access to current research and international developments, particularly in health-related areas. According to Lejeune (1994)

The administration of folic acid is not a treatment but a kind of prevention. It does not change the motor but gives a better use of the fuel. In the long run, we are not concerned about academic performance but about helping those children who are amongst the most disinherited of the children of man ... As regards folic acid: to the best of my knowledge today I would think that we should give folic acid between a half and one milligram per kilogram per day (p.7).

While use of MSB and piracetam are controversial issues for children with Ds, medical programs are approved for children with Ds in western societies such as Australia, including cosmetic surgery, such as facial surgery and necessary surgery such as heart operations. For example, one child had cosmetic surgery in which the surgeon took the slant out of her eyes, and the extra fat out of her cheeks. He also augmented the cheek bones and the nose bridge (Email, 1995f). Tongue reduction is another type of surgery that children with Ds may need when a "large tongue may cause poor articulation, and make speech unintelligible" (Dmitriev & Oelwein, 1988, p.60).

Children with Ds in most industrialised societies have access to early intervention programs such as physio therapy, occupational therapy, and speech therapy. Treatment in physiotherapy is aimed at promoting development of gross motor skills, stabilising acute or chronic chest conditions, music imbalance corrections and maintaining optimum performance in all children. Occupational therapy is aimed at providing assessments and programming for children with developmental difficulties- physical and sensory- from a few months of age, through to school-aged and young adults (St Giles, 1995).

Children with Ds have difficulty in learning language and are delayed in speech. Speech therapy is a useful way to improve the child's speech. Although health services such as therapies have positive effects on children with Ds, in Eastern countries these services are not provided to all children, and in Western countries such as Australia, there is not adequate access to health services in rural areas (Sarantakos, 1998).

2.13.3 Society

Children with Ds are generally considered within society to have a significant disability. Thus, they do not have the same opportunities as other children. First of all, laws do not protect them from being killed before they are born. For example, according to the *Abortion Act* (1990) in England, termination is legal if a foetus is diagnosed as having a disability. In other words "termination for 'normal' foetuses is not legal after 24 weeks' gestation; after which the foetus is deemed to have rights as a human being. "These rights are lost once the foetus is diagnosed as being disabled" (Morris in Ralph, 1994, p.4). Secondly, they are more often seen as weak, or as "cripples" within society because they are different. When differences in individuals are valued negatively in society, they are seen as deviants.

Wolfensberger (1983a) stated that how a person is perceived affects how that person will be treated, which has the following implications:

1. Devalued people are liable to be rejected on any perspective including growth, health, wealth, and life span.
2. The label that is used for a devalued person by society determines the expectations of society.
3. How society treats a person affects the person's reaction towards society.

Socratic (1995) asserted that there is special relationship between the professions and society that yields professional autonomy. It may be concluded that professionals influence the attitudes of the society toward children with Ds.

2.13.3.1 Professionals

Professionals play a special role as both members of society and service providers. Health professionals such as gynaecologists, paediatricians, nurses, and social workers are those who may inform the mother for the first time that her child is with DS. The attitude and manner of health professionals can be meaningful or meaningless to the mother depending on the words and manner that these professionals use to inform the mother about DS. For example, a mother with a child with DS writes:

My son was not a month old yet and the expert to whom we were sent by our community hospital did more to destroy the hope than anyone else that I have met since. Sure I have met people that were ignorant about DS and said that he would be cured. You expect that from persons who do not know about the syndrome. But to be treated by an 'expert' the way we were, it is Unacceptable and I will never forget (Email, 1996).

Many professionals see themselves as eligible to make decisions for people with a disability. Bishop (1987, p.98) stated that people with a disability "have been taught their role in life is to be passive, asocial, [and] submissive to the professionals making the decision for them". Barton (1991) cited Boston (1981) who wrote about the feelings of a mother who gave birth to a child with DS. This mother expressed:

It would appear that consultants tell parents so little for a variety of reasons. Firstly, the medical profession assumes that a little knowledge to a lay person is a dangerous thing and therefore it is better to tell nothing at all, and failing that tell only the bare essentials. Secondly, I got the feeling that they did not think we could 'take' any more information. Finally, although paediatricians may well be versed in the physical problem associated with [Down syndrome] they are concerned only with the child's whole being. The child's body is thus conveniently divorced, for medical purposes, from its human social context (pp.53-54).

The above example suggests that there is a gap between what parents of a child with DS need and what professionals think parents with a child with DS need. Parents

need to know the seriousness of disability of their child. They expect to have accurate and up-to-date information through professionals.

Other health professionals such as orthopaedic surgeons and neurologists have a sensitive role to minimise or correct medical problems. Professionals in early intervention who may work directly with the child include speech therapists, physiotherapists, occupational therapists, social workers, teachers, and psychologists. For example, a speech therapist assists the child with Ds to correct speech and language, a physiotherapist promotes functional mobility, an occupational therapist assists the development of functional daily living skills such as dressing (Ashman, 1998) and the function of a social worker is to provide any necessary support to the family. The social worker will also be able to advise families about their welfare rights and additional services available through the Social Service Department and local authorities (Stratford, 1989). Morrison and Polloway (1995) discussed that

trained personnel can provide services such as physical or occupational therapy in addition to services related to developmental and educational needs (p.254).

During 1970s in Australia, there was expressed concern with the movement of people with a disability from institutions into smaller community-based accommodation. In all states, except Western Australia, personnel working with people with a disability including nurses were trained for three years, and awarded a certificate in either mental retardation nursing or psychiatric nursing. In West Australia and Tasmania, there are courses for social trainers. In Queensland, these personnel are called 'residential care officers'. Australia has been slow to train personnel in vocational programs (Brown, 1988). Obviously training staff in vocational programs should be considered more seriously for people and children with a disability due to the effects that it has on the quality of life of these people and children.

The life story of Sandra Jensen, former president of Capital People First (a committee for self-advocacy and quality of life issues in California) is a worthwhile

example of the many true stories about how some professionals in modern society devalue a child with Ds. This is included in appendix B.

2.14 Summary of Part B

The literature reviewed revealed that one of the aims of social work is to improve the quality of life of people with or without a disability through presenting services. Among professionals, counsellors, nurses, paediatricians, gynaecologists, or social workers usually have first contact with the mother. As the child develops and commences schooling, educators in education also have a significant role to make the school an interesting and developmentally stimulating learning experience. The main points include:

- **Parental issues:** Parents need to know the seriousness of disability of their child. They expect to have accurate and up-to-date information through professionals. Parents expect that following a period in education, their children with Ds are able to interact effectively with others in society, accepted by society and able to work in the same environment as those without disabilities.
- **Services:** According to WHO less than 3% of adult or children with disabilities receive rehabilitation of any kind. Early intervention for children with Ds is effective in reducing the need for special services and developing skills such as social skills and self-help skills toward having a normal life as much as possible. Although in Australia, early intervention and school age education are the constitutional responsibilities of the state government, a significant number of children with a disability do not have access to early intervention and education, especially in rural areas.
- **Society:** The attitudes of society are not positive towards children with Ds and there are still children who are segregated from society.

- Professionals: They play a special role as both members of society and as service providers and there is a gap between what parents of a child with Ds need and what professionals think parents with a child with Ds need.

In chapter 3, theories which underpin the study are presented including the theory of normalisation, quality of life, and the issue of disability as a socio-political construct. Topics which relate directly to the aim of the study are discussed including social theories of disability, and theory of normalisation, followed by a discussion of quality of life, and mothers' perceptions.

Chapter 3.0

Conceptual and Theoretical Frameworks

3.1 Chapter Overview

In this chapter, the overarching conceptual orientation driving the study and the main theories that underpin the study are described. These include the theory of normalisation, 'quality of life', and the issue of 'disability' as a socio-political construct. The chapter includes:

- definitions of quality of life;
- consumers' perspective as a valid mean;
- research in social work; and
- research questions.

3.2 Social Theories of Disability

A range of social theories of disability has been developed (Abberley, 1987; Borsay, 1986; Hahn, 1986; Oliver, 1986). Fulcher (1988) who supported a social theory of disability, agreed with Shapiro (1981, pp.86-87) who stated "if we want to politicise the concept of disability, that is to interrogate the norms for responsibility, authority and power embedded in the discourses that contain it, we must reflect on the ways that disability is constituted in utterances".

In short, Fulcher (1988) argued that there are four discourses on disability: charity, lay, medical, and rights discourses. Charity, lay, and medical discourses have been the traditional discourses, and medical discourses penetrate both charity and lay discourses. In the charity discourse, disability is a personal problem and through philanthropic activities such as non-government organisations, people with a disability are protected because it is assumed that they need help and protection. Lay discourses also consider disability as a personal problem, and are informed by

medical and charity discourses. Marles (in Fulcher, 1988) asserted that it is these themes of fear, pity, prejudice, and ignorance which are oppressive.

Medical discourses individualise disability and see it as a technical issue that is a matter for only the professional judgement of those who think they know best. "Professionalism pervades medical discourse and its associated discourses; psychology, social work, occupational therapy, rehabilitation counselling, physiotherapy and educational discourse" (Fulcher, 1988, p.27).

The rights discourse challenges the traditional discourses, and unlike charity, lay, and medical discourses, is based on self-reliance, independence and consumer needs. Fulcher argued that the "a rights discourse is seen as the most progressive and obvious strategy for those excluded from full citizenship in modern welfare states, including those called disabled" (Fulcher, 1988, p.31). A rights discourse is consumer based and emphasises independence, equality and self-reliance. It is the opposite to concepts of oppression, discrimination and exclusion. A rights discourse emphasises the right to have equal opportunity, the right to be noticed for ability (not disability) and the right to control over their own lives. But there is evidence of the failure of this discourse as in Fulcher's examination of the effects of different institutional practices in Britain and Australia. It is not within the bounds of this discussion to argue this affirmation.

Although there has been a positive change as evidenced through recent models of disability, people, including children with disabilities, seem to be disadvantaged in some societies because the traditional models of disability, charity, lay, and medical discourses, are still accepted by many people. From a medical perspective, labels such as 'cripple', 'handicapped', and 'retarded' do not give a positive opinion about disability (Barton, 1994). Besides, in some cases, people with disabilities are considered "less than a whole person" (Abberley, 1987, p.9). In a society that believes in an individual's rights regardless of their ability, a change in attitudes could abolish disability. Therefore it should be accepted that if people with disabilities "are to

return to the world, we must change" (Barton, 1989, p.166). There has been a recent trend in terminology in writing 'people with disabilities' or 'people with a disability' instead of the traditional form 'disabled people', as it is considered that people are first, disability second.

3.3 Theory of Normalisation

The principle of theory of normalisation, presented by Wolfensberger (1972) and others is the concept of preventing, minimising, or reversing societal devaluation. Since deviance is culturally defined, professionals may aim at enabling a devalued person in society, by reducing stigma, and changing perceptions. Wolfensberger believed that social role enhancement is the ultimate goal, while reducing stigma and changing perceptions can be achieved through the enhancement of the social image of a person and his/her competence both physically and intellectually. Culturally valued means are important for the following reasons:

- images are very transferable phenomena,
- if services are familiar and positively valued by recipients, recipients are apt to relate much better to services,
- habits and skills are difficult to acquire in settings that are culturally alien, and
- staff and families are less likely to support a human service program that is unknown and culturally alien (p.4).

According to Wolfensberger (1983a), there are two ways to schematicise the principle of normalisation. One way is to classify its implications into different levels of social systems: actions on the level of the person, the person's relevant primary social system such as family, and actions on the level of society such as society's values. A second way is to break the principle of normalisation into seven major strategies as follows:

(1) The role and importance of (un)consciousness in human services: It is generally agreed that human beings function with a range of consciousness such as memory and motivation, and unconsciousness, such as routine acts and habits, relating to our environment. Unpleasant situations have negative values and are to be denied unconsciously. This strategy indicates that parents and professionals perceive the birth of a child with Ds as a negative situation that is far from normal life. To investigate this situation, the question that must be asked is: How do parents find out that their child has Ds? Stratford (1989) addressed this in a study of parents with a child with Ds who reported that "there was delay and evasion before the diagnosis was made known ... babies were taken away from the mother immediately after birth. There was no explanation given to the mother for parting the child from the mother. Parents were only told that there was something wrong with the child. These children were put in special care nurseries and were deprived of being raised in a family environment" (p.94).

Clearly the way in which parents find out their newborn baby has Ds may affect their initial reaction towards the child. Therefore, answers to questions about who informs the mothers (a doctor, a nurse, a social worker, or a friend) when the mother is informed (before the birth of the baby in case of amniocentesis, right at the birth, after the birth of the baby, or not told at all) and how (under what conditions, with what words and emotional overlay) are important in order to understand whether the situation is complicated or not for the mother. Stratford (1989) stated that parents "report dissatisfaction with the way in which they were first informed of their child with Ds" by professionals (p.94). He asserted that the "theme of 'parental guilt' is ancient, and has haunted parents through the ages" (p.101). The question is that if health professionals convince the mother that the new born baby with Ds will bring happiness and joy to the family and they give an optimistic perspective to mother, would the mother feel so much fear and guilt? The question raised is why the literature posits parental guilt as such a common feeling? Answers to questions

about later parental emotional problems in relation to their child with Ds are important to determine in the content of parental guilt.

Like Stratford, Cunningham and Sloper (1983) believed that feelings of guilt, rejection of the child, and wishing the baby were dead are universal and "are natural reactions to the situation". Professional perceptions are influenced by medical discourses on disability which individualise disability and see it as a technical issue, or a matter for professional judgement.

(2) The relevance of role expectancy and role circularity to deviancy making and deviancy unmaking: The social roles that people place on each other are powerful social influences. Wolfensberger (1983a) asserted that there are at least five powerful media through which role expectancies can be conveyed:

... the way people structure other people's physical environments; the activities that are offered to, provided for, or demanded of people; the language that is used with and about them; the way people are juxtaposed to each other; and other images and symbolisms (p.7).

When a person is socially devalued, their role expectancies are negative ones. Role expectancies such as those of student, friend, and citizen should be defined and extended to these people. According to this strategy the social roles that people place on each other are powerful social influence. Due to the physical and intellectual deficiencies of a child with Ds, many parents and professionals do not have a positive expectation. Newton (1992) suggested that doctors should be more positive about disability. It is interesting to note that in 1979, "the professional view was that the majority of children with Ds were not capable of learning to read at all" (Newton, 1992, p.8). Answers to questions about parents' social and emotional problem dictums may be related to the types of attitudes of professionals

(3) The conservatism corollary of normalisation: Many people have negatively valued characteristics but they are not placed into a deviant role. In contrast, devalued people are in a state of further devaluation and negative experiences. For example, if a person cannot walk properly or has vision or hearing disabilities, an

observer who sees this person would think that the person has a problem and is different from the rest of the people. Therefore, people can be stereotyped on sight and devalued people need to know life conditions that are highly valued, and what is called normal for the members of society. This strategy discusses the characteristics of people. No one is perfect, but many people with a disability including children with Ds are recognisable by their appearance and are perceived as devalued persons whereas they need a situation in which society views them with positive attitudes. Again, answers to questions about parents' social and emotional problems are important in order to investigate the attitudes of others in society.

(4) The development model and the importance of personal-competency enhancement: Devalued people may be limited in competence because they are subject to low role expectancies. They are segregated from the rest of society, and are grouped with other devalued people. Normalisation requires that the personal competencies of devalued people be enhanced. Wolfensberger discussed this strategy, and stressed increasing the competence of the person with a disability. Considering that a child with Ds has physical and intellectual limitations, society subjects them to low competence whereas it is highly important to increase these children's competence.

(5) The power of imitation: "Imitation is one of the most powerful learning mechanisms known" (p.10), but devalued people do not have the opportunity to model themselves on other people in the society when they are segregated and grouped with other devalued people who have low role expectancies. For example, children with a disability do not have a chance to be with other children without a disability. Normalisation requires the dynamic of imitation in a positive way. Therefore, devalued people are provided with role models who function appropriately. This strategy is consistent with the character of children with Ds. If children with Ds have the opportunity to model positive roles, their situation would be improved.

(6) The dynamics and relevance of social imagery: Historically, devalued people are surrounded by symbols and imagery that “present culturally negatively valued qualities” (p.10), and influence role expectancies. Normalisation implies the expression 'as much as possible' in order to convey positive image messages about devalued people. Therefore, the location of a service program, the staff and the type of program are important and should be consistent with the expectations of valued people. Concepts, such as charity may have negative imagery and should be avoided. Thus, devalued people will be more highly valued. This strategy asserts that the aim is not the concept of being normal, but that a child with Ds should be given the opportunity to have a normal life as much as possible.

(7) The importance of societal integration and valued social participation: When human beings encounter a disliked person or unpleasant situation, they prefer to place a distance between themselves and the unpleasant situation. This is one reason why devalued people may become rejected and segregated. The segregation has immediate negative effects on the people who are segregated. Normalisation requires that devalued people should have the opportunity for integration into society. The last strategy emphasises the integration of a child with Ds into society meaning integration into the daily activities of life such as school, and the community.

The normalisation principle has been criticised for imposing cultural uniformity, whereas it promotes social tolerance and enables many people who have been devalued to participate, it also encourages integration instead of segregation. Wolfensberger (1983b) described the goal of normalisation as clarifying the establishment, through the enhancement of social images and personal competence of people who have been devalued by society. He also concluded that a better term for normalisation is 'social role valorisation'. He asserted:

I believe that adopting this new term is not only a more accurate description of what the theory of normalisation has been all about, but that just as importantly, the phrase can serve as a very instructive consciousness raiser

to those who hear and use it (p.238).

However, the term 'normalisation' is used worldwide, and in recent literature writers such as Casey (1994), and Ashman (1998) preferred to use term normalisation.

Fullagar and Hardaker (1993) discussed disability services implementing social role valorisation and normalisation models, and suggested a theoretical approach based on liberator notions of empowerment and social change. They argued that the theory of social role valorisation (SRV) "offers powerful insights into the process of systematic devaluation which has been inflicted upon people with an intellectual disability". Their main question is : "What right do we have to attempt to change a person's manner, appearance or activities ostensibly to make other people feel more comfortable?" (p.37). This question seems logical, but the goal and concept of normalisation is not to make other people feel more comfortable. In addition, concepts such as tolerance, respect, and equity discussed by Fullagar and Hardaker are in common with themes developed by Wolfensberger.

In Iran, the theory of normalisation has not yet been practiced. Children with a severe disability are often kept at home and if the parents are unable to care for the child, the state welfare organisation will institutionalise the child. Children who are able to physically move attend special schools and are not permitted to attend government schools. Recently, with the permission of the Ministry of Education, some private schools, with the efforts of parents, have been permitted to register children with special needs.

In Australia, 'de-institutionalisation', one of the principles of normalisation, has existed since 1980. At the 17th Australian Conference for People with Intellectual Disabilities Australia (1981), de-institutionalisation was introduced as a successful strategy in normalising the lifestyle of people with intellectual disabilities (Jewel, 1982, p.234). Again at the 1992 Australian Creative Recreation Consultants Conference, studies presented the positive influence of normalisation (Little, 1992).

Despite all the benefits of normalisation, as a theory it does not meet all the needs of people with a disability. For instance, while people with a disability are given all rights to live in the community, they may get less care in the community than in institutions. In Australia, one of consequences of de-institutionalisation has been an increased pressure on families who house their child with a disability at home. Baxter (1989 in Parmenter et al, 1993) investigated the needs of these parents and realised that a majority of parents needed to receive appropriate information about the child, but “never received direct support from agencies” (p.89).

3.4 Quality of Life

While writers such as Bayer et al (1988), Brown (1988), Kohli (1988), and Macfarlane (in Brown, 1988) have defined the term 'quality of life' positively, writers such as Wolfensberger believe 'quality of life' has a false base.

Shallock (Brown, 1995) stated that quality of life is a concept that “reflects a person's desired conditions of living” (p.1). Brown (1988) defined quality of life “as the discrepancy between a person's achieved and their unmet needs and desires. The larger the gap between what people have and what they need and want, the poorer their quality of life” (p.111). Brown (1995) defined the quality of life as having two components, “One, the discrepancy between a person's achieved and unmet needs and desires and, two, the extent to which an individual increasingly controls aspects of life, regardless of original baseline” (p.1). Brown (1995) argued that subjective indicators of quality of life which are based on an individual's perception are preferred to objective indicators of quality of life which have a biological or psychological base. A new definition of quality of life is “the degree to which the person enjoys the important possibilities of his or her life” (Woodill et al, 1993) and according to this definition

The QOL of an individual is intrinsically related to the QOL of other persons in his or her environment ... QOL of a person reflects the cultural heritage of the person and of those who surround him or her (p.67).

While Brown (1988) identified four dimensions of quality of life, Hegarty (1993) has identified three dimensions: personal characteristics (such as educational level), objective indicators (such as income level), and subjective indicators (such as health satisfaction), (p.243).

Like Brown, Hegarty has indicated that subjective indicators are more important than objective indicators to identify quality of life. To know how the quality of life can be improved "one has to discover which factors exert a positive or a negative influence" (Nordenfelt, 1994). For example, health and education are two important factors that influence the quality of life. For the ancient Greek philosopher Aristotle, health was an element of happiness and happiness was a part of quality of life. Happiness as associated in ancient times is divided into a social aspect (welfare) and a psychological aspect (well being).

The welfare concept is often connected with sociological research, where it is used to describe living conditions in societies. The well-being concept is often connected with psychology and is used to capture different pleasant cognitive and emotional states. The health concept is connected with the medical research area and is used to describe the differences between illness and health and the functional losses caused by illness (1994, pp.258-259).

Unlike other authors (Cummins, 1992; Goode, 1990) who discussed QOL positively and suggested models of measuring QOL, Taylor (1993) argued that the concept of QOL has its roots in the Western culture which is based on individualism. He emphasises the importance of the philosophical implications of quality of life, and suggests avoiding defining and measuring QOL. Wolfensberger (1993) argued for the abandonment of the term 'QOL'. He reviewed seven problematic uses of the term 'QOL' in his critical paper : "Let's hang up 'Quality of Life' as a hopeless term" (p.285), and provides evidence that 'QOL' is misused and misunderstood.

But the term 'QOL' like 'normalisation' is well known. It is not possible to abandon the 'QOL' term suddenly, especially as there is no general agreement to do so. However, the main issue that Wolfensberger points out; "... to take QOL talk

away from the deathmakers" (1993, p.318) sounds logical since there is a "shift from a qualitative view of the value of human life to a quantitative one..." (p.300).

Wolfensberger cited two example of this shift; the first is that of Joseph Fletcher who asserted in 1972 that the minimal intelligence necessary to have quality as a person is an Intelligence Quotient (IQ) of 40, and the second was in 1973 when the US Supreme Court ruled that "... unborn children were not persons ... and could be killed on demand by their mothers" (p.301).

In this study, quality of life is related to factors which improve the living conditions of a child with Ds and so is related to physical and psychological development. Physical and psychological developments in turn are related to social service programs. In fact, the availability and quality of social service programs can influence physical and psychological development. In this study, three perspectives of quality of life (the philosophical, medical, and social perspective) are discussed.

In the philosophical perspective, topics such as eudemonistic and equalitarian utilisations are examined (Aiken, 1990, p.17). In eudemonistic use, no attempt is made to compare different grades of quality but to manifest an advisable level of quality of life. This advisable degree is interpreted by words such as 'happiness', and 'beatitude'. In an equalitarian use of quality of life, liberty is a prerequisite to maintain a human quality of life. The belief in liberty is considered as an important state to follow 'happiness'. Although 'liberty' is a necessary element to achieve happiness, liberty and freedom alone do not guarantee happiness of life by Aiken. However, a pattern common to both the eudemonistic utilisation and the equalitarian utilisation is that human beings should acquire an advisable rank of quality which augments and prepares for the desired level of quality of life. Therefore, from philosophical perspective, it is acceptable to think about a desired level of quality of life.

From the medical perspective, terms such as euthanasia, and abortion are included. Within this perspective, if a person's quality of life is below the agreeable

level, his or her life may be considered as not worth living. This is similar to the debate to justify abortion when a foetus is considered not to be sufficient and therefore, is not capable of achieving a happy life. If this argument is valid, then it may be extended to justify termination of those with mental or physical disabilities. Thus, within the medical perspective, where quality of life of people with a disability is denied by health professionals, this perspective is thus inconsistent with elements of social justice, such as equity, equality of rights, access to services, and participation (Salvaris, 1990).

From the social perspective, a comparison of the measurable degree of quality is made. Social scientists manifest a quality of life measure analogue to the Gross National Product measure by finding indices of social well-being to the economic indicators of economic well-being (Aiken, 1990). Blunden (1988) discussed four dimensions of quality of life as follow:

- physical well being: health, fitness, absence of disability,
- cognitive well being: satisfaction with life, positive 'story',
- material well being: adequate income, a home, means of transport,
- social well being: community presence, choice, competence, respect, and valued relationships (p.37).

The above dimensions indicate that quality of life is related to physical and psychological aspects.

Quality of life refers to a person's perception of his or her life. What a person feels, and how they image their life are important for the defining personal quality of life. Nordenfelt (1994) stated that Samuel Ordway at the beginning of the 1950s was the first to use the term 'quality of life'. The idea of human need characterises the concept of quality of life in many allied and health care discussions. For example, in psychology, Maslow's (1954) system of hierarchy of needs was an attempt to characterise the basic needs of a human being.

Four dimensions of quality of life of a child with Ds are physical and cognitive well being, the attitudes of society, socio-demographics of the family such as parents' age, education, and job, and the availability of services such as education and health programs.

The physical well being of the child is related to physical characteristics and sensory motor skills and have been discussed previously. Sensory motor skills and cognitive well being can be improved through early intervention programs from birth. Material well being depends on the economic situation of the family which is partly related to the quality of welfare state programs.

Social well being is partly related to the theory of normalisation. The researcher has noticed during her work with children with Ds in Tehran, for example, that the availability of services and the attitudes of both the child's family and society can affect positively or negatively her or his level of disability, which in turn affects her or his quality of life. In industrialised countries such as Australia, with better educational and health care programs, children with Ds are healthier, learn faster, and live longer. An example of longevity has been addressed by Stratford (1989) who stated that in 1985, the mean survival age for people with Ds was 40+ in England, compared to 9 years in 1932. In the US, adults with Ds can expect to live healthily into their 50s or 60s (Pueschel, 1992). But, the basic conditions for children in developing countries is lower than that in industrialised countries. For instance, in the middle eastern family when a child with a disability is born, parents often feel guilt and shame. "Guilt is felt by the mother" because she is responsible for the birth of her child, and the father feels shame because he sees his child as a symbol of failure to the dignity of his family in the eyes of the society (Sharifzadeh, 1992, p.340). Because children with Ds are devalued by society, they do not have a desired living condition, although health and educational programs can have an important role to enhance their living condition. Brown et al (1994) believed

that "improvement of living conditions is often a top priority for individuals who are mentally unstable ..." (p.142).

In conclusion, the definition of quality of life by Brown et al (1988, p.111) is explicit and clear because it considers the discrepancy between a person's achieved and his or her unmet needs and wants. Thus, justification for investigating the quality of life of children with Ds, their actual living conditions and their unmet needs is supported.

3.5 Mothers' Perceptions

Since mothers usually spend the most time with their child in the early years, they play an important role in explaining the interests and activities of the child to professionals. Therefore "parents are accurate assessors and predictors, a resource, providers, and client-consumers of a service delivery system" (Cunningham & Davis 1985, p.xi).

The importance of the consumer's perspective has been emphasised in several articles (Brown, 1994; Halpern et al, 1986), and the belief in the 1990s is that "a person's perception of his or her quality of life is an integral part of service delivery and the evaluation of habitation outcomes" (Schalock, 1993, p.266). Kettner , et al (1990, p.113) emphasise consumer satisfaction , and define the elements of a social service program, dividing it into its input, throughput, output, and outcome elements.

Inputs include five elements: clients, staff, material resources, facilities, and equipment. Throughput refers to service delivery process. An output of a social service is defined as the completion of that service by the client ... An outcome is defined as a measurable change in quality of life achieved by a client between entry into and exit from a program (pp.119-120).

Reif (1993) discussed three additional QOL principles undertaken by the national study (NQOLP):

1. QOL is largely a social phenomenon and primarily a product of interaction with others, This requires a social ecological definition of QOL for the

- individual that incorporates the QOL of significant others in the setting
2. QOL is the product of individuals with disabilities meeting their basic needs while fulfilling their responsibilities in community settings (family, recreation, school and work). Individuals who are able to meet their basic needs while fulfilling responsibilities in ways that are satisfactory to themselves and to significant others in the setting are more likely to experience a high quality of life and;
 3. QOL is a matter of consumer rather than professional definition. QOL issues should be defined by consumers and other citizens rather than by professionals in the field. Ultimately it is how the individual perceives and evaluates his or her own situation, rather than how others perceive it, that determines the QOL he or she experiences (p.239).

To emphasise the importance of parents' perceptions, staff of the Children's Hospital of Buffalo in the US believe that "the parent's perspective of their performance is important now and in the future" (Email, 1995d).

In 1983, Disabled Peoples' International, Disability Advisory Council of Australia, and Handicapped Programs Review were new programs for people with a disability in Australia. The focus of Handicapped Programs Review and the *Disability Services Act 1986* was to announce seven positive consumer outcomes important for the development of people with a disability. The key outcomes were: a place to live, paid employment, competence and self-reliance, community participation, security, choice, and positive image (Parmenter et al, 1993, p.77).

The *Disability Service Act 1986* emphasises choice and participation in decision-making . Only recently has Australian research discussed the topic of 'choice' for people with a disability, a key component of quality of life. According to Parmenter, et al (1993)

There is evidence to suggest that people with an intellectual disability are less likely to have a free choice about certain major life decisions, ... although Australian legislation has given prominence to the values of choice, autonomy and involvement for Australian citizens with an intellectual disability, there is an alarming gap between policy and practice" (87).

As the literature suggests, there is a gap between policy and practice.

3.6 Summary

In this chapter the overarching conceptual orientation driving the study and main theories which underpin the study were described, and the following main points emerged:

- **Disability:** Disability is not a personal problem and all people with a disability, including children with Ds should have equal opportunity as others in society. There is a gap between policy and practice.
- **Professionals:** They often perceive the birth of a child with Ds as a negative situation, and assert that the theme of parental guilt is ancient and common. In fact, answers to questions about parents' emotional problems are important to find out about roots of parental guilt.
- **Consumers' definitions:** Consumers' definition are preferred to professionals' perceptions and Parents' perceptions are emphasised as a valid means. Since mothers spend the most time with their child in the early years, and children in this study are from birth to 12 years, mothers were interviewed.
- **Quality of life:** For investigating the quality of life of children with Ds, their actual living conditions and their unmet needs should be examined. Thus, answers to questions about family background, family's social and emotional problems, availability of services are important factors to find out about the actual living conditions of children with Ds. Answers to questions about satisfaction with services, family's special needs, and improvement are factors to identify unmet needs.

3.7 Research Questions

The aim of this study was to study the living conditions and quality of life of children with Ds based on mothers' perceptions about social services and their experiences of having a child with Ds. Although previous studies (Cunningham & Sloper, 1983; Newton, 1992 ; Stratford, 1989) revealed that parents have a range of

mostly negative reactions due to having a child with Ds, the main cause of these feelings has not been addressed in the literature. Three main questions guided this study:

- 1- What factors influence a mother's perception of social services provided for her child with Ds?
- 2- What are the critical factors that determine the level of quality of life of children with Ds as perceived by their mothers?
- 3- What conclusions can be drawn from an examination of the lived experiences of Australian and Iranian mothers of children with Ds?

In the next chapter, chapter 4, the research methodology is discussed. This includes case study and survey research methods, and outlines ways that data was collected in Iran, Tasmania, and Mainland Australia. Ethical considerations and validity and reliability of the study are described. Finally, the process undertaken in the analysis of data is explained.

Chapter 4.0

Research Method

4.1 Chapter Overview

Chapters 1 and 2 provided the context of the research problem by defining key terms, and discussing the nature of Down syndrome with particular emphasis on the physical and intellectual characteristics of children with Ds. Background material to the study was analysed through a review of the literature, which suggested that;

- many professionals lack accurate information on Ds;
- there are negative attitudes in society towards children with Ds and their families;
- inadequate social services affect early intervention health and education programs after the birth of children with Ds, which are seen as important to the quality of life of these children and their families.

These issues present barriers to mothers of children with Ds. The review of the literature informed the development of key questions to be investigated to assess the quality of life of children with Ds from the perception of mothers of children with Ds.

This chapter will focus on the research method, which includes case study, interview and survey research methods conducted in Iran, Tasmania, and Mainland Australia. The ethical considerations and validity and reliability of the study are described and the process undertaken to analyse the data is explained.

4.2 Method

Due to the nature of the problem, a qualitative and interpretive method was adopted. Qualitative researchers search strategies of empirical inquiry for making connections among lived experiences (Yegidis & Weinbach, 1991). Qualitative research is both old and new in social science. According to Patton (1990), personal contact and insight, inductive analysis, empathic neutrality, and design flexibility are

some of the characteristics of qualitative research. Lincoln and Guba (in Patton, 1990) believed that naturalistic inquiry is the only valid and meaningful way to study human beings. Both the naturalistic approach and the positivistic approach can contribute to the knowledge base that is the foundation for social work research and practice, and both have a place in the methodology of social work research.

Since the primary purpose of this research was to study the actual living conditions of children with Ds, the method is one of formative evaluation, "to improve human intervention within a specific set of activities at a specific time for a specific group of people" (Patton, 1990, p.156).

Case studies, including participant observation and interviews were used in order to validate and cross-check the findings.

Schwandt (1994) proposed four criteria for assessing the quality of the research as

- the trustworthiness criteria of credibility (paralleling internal validity),
- transferability (paralleling external validity),
- dependability (paralleling reliability), and
- confirmability (paralleling objectivity).

Miles and Huberman (1984) stated that "by multiplying independent measures and sources of the same phenomenon, informants make the same claim independently" (p.438). Patton (1990) proposed a multimethod, triangulation approach to fieldwork to increase the validity and the reliability of evaluation. Janesick (1994) cited Denzin who identified four basic types of triangulation: data triangulation, theory triangulation, investigator triangulation, methodological triangulation (p.214).

In order to provide grounds for validating the observations and generalisations, in this study, a process of triangulation was used. The validity of and confidence in the findings were addressed by multiple data sources, and multiple methods.

4.2.1 Case Study Research

Case study is a method of organising data for the purpose of analysis of phenomena in real-life situations; it can be qualitative or quantitative or a combination of the either (Stake, 1994). Yin (1989) defined a case study as an empirical inquiry that:

- investigates a contemporary phenomenon within its real-life context; when
- the boundaries between phenomenon and context are not clearly evident; and in which
- multiple sources of evidence are used (p.23).

Yegidid and Weinbach (1991) stated that "case study has been and remains a favourite among social work researchers... the advantage of the case study is that the knowledge of feelings and perceptions can be acquired which is not available when using other designs" (p.97). The use of observational methods requires disciplined training and rigorous preparation. Stake (1994) identified three types of case studies:

- intrinsic case study; when a researcher wants to have a better understanding of a case,
- instrumental case study; when a specific case is examined in order to provide insight into an issue, and
- collective case study; when we study a number of cases together in order to investigate a phenomenon, condition, or population (p.238).

The methods of data collection with which qualitative research is associated have been employed by social scientists for many years. One of the best known of these methods is participant observation which is used when social workers act as both researchers and as a member of the group. The use of observational methods requires disciplined training and rigorous preparation.

The strength of naturalistic inquiry is that the observer is sufficiently a part of the situation to be able to understand personally what is happening and the degree of participation varies from full to marginal. When the researcher has a natural role in the program, she or he has full participation whereas when the researcher comes to the group from outside, the degree of participation is marginal. Overall, it is

essential that the researcher builds a relationship of trust with the respondent (Patton, 1990).

In this study, case study research was developed through a process of participant observation and interviews mothers of children with Ds in order to find out the critical factors that determine the level of quality of life of their children.

4.2.2 Interview Research

According to Patton (1990), there are four types of interview:

- informal conversational interview in which questions emerge from the immediate context,
- interview guide approach in which issues are specified in advance,
- standardised open-ended interview in which the same basic questions are asked in the same order, and
- closed, fixed response interview in which "Questions and response categories are determined in advance" (pp.288-289).

In this study, interviews took several forms including informal conversational and open-ended case study interviews in which the investigator asked key respondents facts as well as the respondents' opinions about events. Six kinds of questions were asked:

- 1- Experience/behaviour questions. Questions about what a mother does or has done, and what is her experience of having a child with Ds.
- 2- Opinion/value questions. Questions which relate to opinions about Ds.
- 3- Feeling questions. Questions about emotional and social issues which relate to having a child with Ds.
- 4- Knowledge questions. Knowledge questions about Ds.
- 5- Sensory questions. Questions about what a mother has seen, heard, or experienced because of having a child with Ds.

6- Background/demographic questions. Questions about age, education, and occupation of parents as well as characteristics of the family. A list of interview questions is presented in Appendix D.

4.2.3 Survey Research

Hoffart and Krysik (1993) defined survey research as a process in which data are collected with a survey type of measuring instrument to obtain opinions or answers from a population or sample of respondents in order to describe or study them as a group (p. 450).

In this study survey research was developed through a questionnaire (Appendix E) in order to provide information on the characteristics of each family and to examine the experiences of mothers including their problems and needs while raising a child with Ds.

4.2.4 Pre-tests

Yin (1989) discussed that a pilot study helps researchers in refining their data collection plans with respect to both the content of the data and the procedures to be followed. For the interviews in Iran and Australia, a framework of five questions was designed and completed by 10 people; single, parents with a child with Ds and parents without a child with Ds in order to administer the measuring instrument. Also, two mothers of children with Ds were interviewed for one hour using a tape recorder. After reading all the answers to the questions as well as reconsidering the literature, the interview framework was revised and seven more questions were added. Then the revised framework was administered by interviewing three more mothers to ensure it reflected complete feelings and experiences of mothers raising a child with Ds. None of the pre-test participants were included in the study. Due to cultural and resource differences between Iran and Australia the wording of some of questions was changed for Australian conditions.

The questionnaire was designed, in accordance with interview questions, and given to a group of mothers in Tasmania to test. After revising some of the questions in a clearer direction it seemed to be perceptible.

4.3 Participants and Procedures

The focus of the research was mothers who had children with Ds and the provision of social services for them and their families. The age of children was from 9 months to 12 years. Although it may be reasonable to assume that due to developmental differences there should be different needs and services for children within this age group, however their basic needs are the same.

The sampling strategies used in this study to develop case studies were:

- purposeful sampling;
- criterion sampling, in which all children with Ds from birth to 12 years of age were considered;
- snowball or chain sampling in which mothers with a child with Ds were asked to identify new mothers and the new mothers were contacted and were asked if they knew of other mothers who had a child with Ds; and
- combination or mixed purposeful sampling in which a variety of sources were contacted in order to locate children with Ds.

4.3.1 Iran

In Iran participants were mothers who volunteered from within a parent group and whose children attended an exceptional school. All mothers agreed to participate and the school contained 206 students with different disabilities. Nine case studies were developed through a process of participant observation (4 months period) and interviews. Eleven additional mothers were interviewed for approximately one hour using a pre-tested interview framework (Appendix D).

Participant observation occurred in the playground of the school where; a child was playing alone; a child interacting with a child with a disability; a child interacting with his mother and, a child interacting with staff. Interviews were either conducted in the researcher's office, the mothers' place of work, or the mothers' home.

4.3.2 Tasmania

In Tasmania, participants were mothers whose children attended special school, or early special centers called locations D and E in a major city in Tasmania. All agreed to participate. As in Iran, nine case studies were developed through a process of participant observation (6 months period) and interviews. Eleven additional mothers were interviewed for approximately one hour using a pre-tested interview framework. Participant observation occurred in a play group where; a child was playing alone; a child interacting with a child with a disability; a child interacting with her or his mother and, a child interacting with staff. Interviews were conducted in the researcher's office, mothers' place of work, or mothers' house. All interviews were tape recorded and then transcribed.

4.3.3 Mainland Australia

Questionnaires were mailed to the Australian Down Syndrome Association in eight states and territories of Australia, accompanied with a cover letter and a stamped envelope for returning the questionnaire. The executive officer was asked to circulate these questionnaires.

4.4 Ethical Considerations

Permission to undertake this study was granted in Iran by the relevant authorities. A meeting was held with the principal of the school to explain the aim of the study. After explaining the aim of the interview to mothers, a consent form was given to each

mother to read and sign if they agreed to be interviewed. In Australia, a successful application was made to the Ethics Committee, University of Tasmania to undertake research involving children with Ds and their families in Tasmania. Matters of confidentiality were handled by informed consent and all of mothers signed the form before being interviewed (Appendix C). Hard copies of all transcripts have been kept in a locked cabinet at the University of Tasmania at Launceston, Department of Humanities.

4.5 An Approach to Transcript Analysis

Data analysis consisted of two parts based on an interactive model presented by Miles and Huberman (1984). In the first part, data were computerised with a software package for coding and retrieval. In the second part, data were analysed through:

- data reduction which means summarising, organising, and paraphrasing data,
- data display by using graphs, charts, and matrices,
- conclusion drawing/verification which refers to regulations, patterns, explanations, and propositions (p.22). Figure 4.1 indicates components of data analysis.

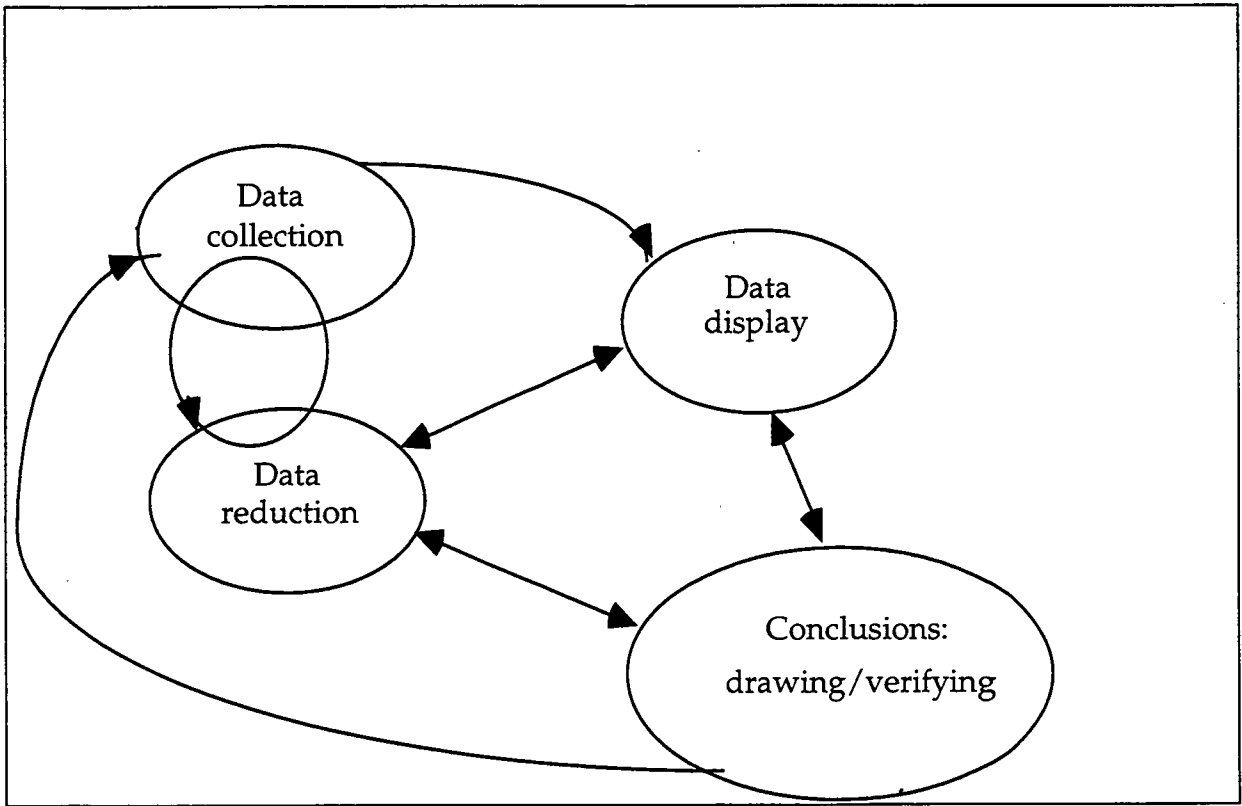
4.5.1 Coding Data

Data was computerised with a software package program, NUDIST, for coding⁶. A document system holds data about documents which may be on-line or off-line documents, and may be segmented for coding. Each individual document, interview and questionnaire transcript was assigned an identifying number and became an individual file within the program to produce three major headings: family, social services, mothers' perceptions as the basis for analysis and interpretation of the data (Appendix F).

4.5.2 Generating Pattern Codes

Pattern codes were generated in order to condense data into fewer components. Each of the eighteen case studies and twenty two interviews were reviewed during and after data collection and was summarised to produce patterns. During the review process, significant parts of data were highlighted on each transcript and was compared with each other. As a result, data was clustered under five sub headings: family background, mothers’ finding out about Ds, emotional and social problems, social services, and mothers’ perceptions.

Figure 4.1: Components of Data Analysis Interactive Model



Source : Miles and Huberman, 1984, p.23

4.5.3 Pattern Codes in Analysis

Of the three ways of using pattern codes, the memo was used (Miles & Huberman, 1984). Memos helped to find out about the relationship between codes.

Several tactics were used in order to draw conclusions. One of the tactics was counting in the form of percentages in order to determine what factors were most significant and important as well as comparing similar data in Iran, Tasmania, and mainland Australia. Another tactic was noting relationships between the variables such as the relationship between mothers' satisfaction with services and quality of life of their children, or the relationship between informing mother about child's diagnosis and mother's emotional problems. In short, data was counted, clustered in order to find factors and relations between factors were noted and then finally, conceptual coherence was achieved.

To test the explanations of the study, tactics suggested by Miles & Huberman (1984) were used. Some of the tactics were:

- checking for representativeness which means filling out weekly sampled case types such as cases where mothers had adopted a child with Ds,
- making contrast which means comparing feelings of mothers who have negative reactions with those who do not have negative reactions, and
- using the extreme case in which the comments of mothers who were experienced and enthusiastic were often utilised as exemplars.

4.6 Limitations of the study

Considering that mothers had the choice of giving more than one answer total percentages could be more than 100%. All mothers were asked the same questions except the mothers on the Australian mainland who were not asked about the way they were told that the child had Ds. Instead, they were asked whether they had any support at the time when they were informed about the diagnosis about Ds. Also, these mothers were not asked about the limitations of having a child with Ds.

Chapter 5.0

Research Findings

5.1 Chapter Overview

In this chapter, the findings are presented under headings determined through the coding process. Each heading contains data from Iran, Tasmania, and mainland Australia for interpretation. The answers of completed questionnaires from Mainland Australia were grouped under the same headings as case studies and interviews. Answers to questions 1, 2, 3, 4, 5, 8, 10, 17 of the questionnaire (Appendix E) were clustered under the heading family. Answers to questions 6, 7, 9 were clustered under the heading services. Answers to questions 11, 12, 13, 14, were clustered under the heading mothers' perceptions.

5.2 Family

The family is the primary social and educational environment for the child. The family, especially parents, have the basic role in forming a child's characteristics.

5.2.1 Family Background

Seven factors, such as, age of the child with Ds, grade at school, the number of children in the family, the position of the child with Ds, parents' age, education and job were identified as demographic family variables (Tables 5.1, 5.2, 5.3).

Children with Ds studied in Iran (Table 5.1) were between nine months to 12 years of age. Parents were between 20 to 57 years old with primary, secondary, or tertiary education. All Iranian mothers who participated were natural mothers.

As shown in Table 5.2, children with Ds studied in Tasmania were between one to 12 years of age. Parents were between 24 to 47 years old with secondary, or tertiary education. Fifteen percent (3) of mothers had adopted their children with Ds.

On the mainland Australia, children with Ds (Table 5.3) were between two to ten years of age. Parents were between 26 to 55 years old with primary, secondary, or tertiary education. Four percent (1) of mothers had adopted their children with Ds.

Within this study 31% (21) of children with Ds were first born, 21% (14) were second born and 21% (24) were third born. These birth order positions account for 72% of all children in this study.

A large proportion, 40%, (16) of Iranian parents (Table 5.4) were aged 40-49 years at the time of the research. Tasmanian parents, 50% (10), were aged 30-39 years, and the majority of parents on the mainland Australia, 46% (26), were aged between 30-49.

As shown in Table 5.5 the majority of Iranian parents, 60% (12) had at least a high school education, all of Tasmanian parents had a high school education, and the 53% (30) of parents on mainland Australia had tertiary education. It should be noted that the Iranian education system is based on pass and fail meaning that only those who pass the national standard have access to further education. Eleven percent (3) of fathers on mainland Australia had only a primary education. This could be due to the old education system, or they might be immigrants from other countries with a

Table 5.1: Iran, Family Background

No	Age (yr)	<u>Child</u>			Age	<u>Mother</u>		Age	<u>Father</u>	
		Grade	No of Child.	Position		Education	Job		Education	Job
1	1	-	1	1	37	Ter.	Home	40	Ter.	Prof.
2	0.9mo	-	1	1	24	Ter.	Prof.	26	Ter.	Prof.
3	8	-	1	1	40	Sec.	Skilled	50	Hi. Sch	Skilled
4	6	-	3	3	43	Ter.	Prof.	45	Ter.	Prof.
5	10	3	3	3	46	Ter.	Prof.	50	Ter.	Prof.
6	6	-	4	4	45	Hi. Sch	Home	50	Hi. Sch	Skilled
7	4	-	3	3	45	Ter.	Prof.	46	Ter.	Prof.
8	2	-	1	1	20	Pri.	Home	24	Pri.	Unskld
9	12	4	5	5	35	Pri.	Home	45	Pri.	Unskld
10	7	1	5	3	30	Pri.	Home	35	Hi. Sch	Skilled
11	9	2	6	6	43	Pri.	Home	48	Hi. Sch	Skilled
12	7	Pre	8	4	45	Pri.	Home	49	Hi. Sch	Semi.
13	9	2	11	7	35	Pri.	Home	50	Pri.	Semi.
14	7	Pre	5	2	27	Hi. Sch	Home	40	Hi. Sch	Semi.
15	8	2	3	1	26	Hi. Sch	Semi.	39	Hi. Sch	Semi.
16	8	2	9	6	41	Pri.	Home	57	Pri.	Retired
17	10	3	4	2	37	Hi. Sch	Home	39	Sec.	Semi.
18	8	2	6	5	33	Pri.	Unskld	46	Pri.	Dec.
19	7	1	2	1	28	Sec.	Home	28	Sec.	Prof.
20	10	3	3	1	30	Hi. Sch	Home	31	Sec.	Semi.

Table 5.2: Tasmania, Family Background

<u>No</u>	Age (yr)	Grade	<u>Child</u>		Age	<u>Mother</u>		Age	<u>Father</u>	
			No of Child.	Position		Education	Job		Education	Job
21	3	—	2	2	29	Hi. Sch	Unskld	32	Hi. Sch	Semi.
22	3	—	2	1	24	Hi. Sch	Home	27	Hi. Sch	Semi.
23	4	—	4	4	37	Hi. Sch	Home	46	Ter.	Prof.
24	5	—	3	1	32	Ter.	Home	32	Ter.	Skilled
25	2	—	1	1	36	Ter.	Prof.	39	Sec.	Skilled
26	8	2	3	2	33	Sec.	Skilled	39	Sec.	Skilled
27	4	—	4	2	38	Ter.	Home	42	Ter.	Prof.
28	9	3	2	2	40	Sec.	Skilled	44	Sec.	Prof.
29	5	Prep.	6	5	45	Hi. Sch	Home	47	Ter.	Prof.
30	5	Prep.	4	4	43	Hi. Sch	Home	35	Ter.	Skilled
31	3	—	3	3	40	Hi. Sch	Home	35	Hi. Sch	Semi.
32	3*	—	3	3	46	Hi. Sch	Home	47	Hi. Sch	Pnsnr
33	8*	2	7	6	46	Ter.	Home	45	Ter.	Skilled
34	5	Prep.	1	1	36	Hi. Sch	Skilled	39	Hi. Sch	Skilled
35	7	Prep.	4	4	34	Hi. Sch	Semi.	36	Sec.	Pnsnr
36	12	7	3	3	39	Hi. Sch	Home	40	Hi. Sch	Skilled
37	7	1	3	2	33	Hi. Sch	Home	39	Ter.	Semi.
38	12	7	4	3	46	Sec.	Home	49	Sec.	Skilled
39	1	—	2	2	48	Hi. Sch	Home	49	Hi. Sch	Skilled
40*	3	—	4	4	37	Hi. Sch	Semi.	38	Hi. Sch	Pnsnr

* = adopted

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Table 5.3: Mainland Australia, Family Background

No	Age (yr)	<u>Child</u>			Age	<u>Mother</u>		Age	<u>Father</u>	
		Grade	No of Child.	Position		Education	Job		Education	Job
41	4	Spe.Sch	2	2	26	Sec.	Skilled	31	Ter.	Semi.
42	5	Prep.	3	3	37	Ter.	Home	40	Ter.	Prof.
43	5	Prep.	3	2	35	Ter.	Home	33	Sec.	Skilled
44	8	Pri.	2	1	49	Ter.	Home	51	Ter.	Self E.
45	8	Pri.	3	1	36	Sec.	Home	39	Ter.	Prof.
46	10	Pri.	2	1	44	Ter.	Prof.	41	Ter.	Prof.
47	7	Pri.	3	3	39	Ter.	Home	42	Sec.	Semi.
48	11*	Pri.	5	5	51	Sec.	Home	55	Sec.	Skilled
49	10	Pri.	3	3	41	Ter.	Skilled	41	Ter.	Prof.
50	10	Pri.	3	2	41	Ter.	Prof.	36	Ter.	Prof.
51	8	Pri.	4	3	35	Ter.	Prof.	36	Ter.	Prof.
52	6	Pri.	3	1	33	Ter.	Prof.	35	Ter.	Prof.
53	13	Sec.	3	3	43	Sec.	Prof.	43	Sec.	Skilled
54	10	Pri.	8	8	52	Sec.	Home	55	Ter.	Prof.
55	9	Pri.	2	1	46	Ter.	Skilled	53	Ter.	Prof.
56	8	Pri.	6	6	48	Sec.	Home	49	Sec.	Semi.
57	7	Pri.	2	1	38	Ter.	Prof.	42	Ter.	Prof.
58	9	Pri.	3	3	43	Sec.	Home	45	Pri.	Semi.
59	10	Pri.	2	1	35	Sec.	Prof.	46	Pri.	Semi.
60	2	--	2	2	37	Sec.	Home	33	Sec.	Skilled
61	9	Pri.	1	1	42	Ter.	Prof.	55	Ter.	Prof.
62	6	Pri.	2	2	41	Ter.	Home	31	Ter.	Prof.
63	8	Pri.	4	4	32	Sec.	Prof.	47	Sec.	Skilled
64	5	--	3	1	35	Sec.	Home	46	Sec.	Skilled
65	3	--	1	1	37	Sec.	Skilled	44	Sec.	Self E.
66	8	Pri.	2	2	42	Ter.	Home	45	Ter.	Prof.
67	6	Pri.	4	4	41	Sec.	Home	42	Pri.	?
68	2	--	2	2	32	Sec.	Skilled	35	Ter.	Prof.

* = adopted

different education system. Overall, the majority of parents in this study have high school and tertiary education.

Table 5.4 : Parents’ age

Parents	20 - 29	30 - 39	40 - 49	50 - 59
Iranian mothers	25% (5)	35% (7)	40% (8)	---
Iranian fathers	15% (3)	20% (4)	40% (8)	25% (5)
Tas. mothers	10% (2)	50% (10)	40% (8)	---
Tas. fathers	5% (1)	50% (10)	45% (9)	---
Mainland mothers	4% (1)	46% (13)	43% (12)	7% (2)
Mainland fathers	---	32% (9)	50% (14)	18% (5)

Table 5.5 : Parents’ education

Parents	Primary	High School	Secondary	Tertiary
Iranian mothers	40% (8)	25% (5)	10% (2)	25% (5)
Iranian fathers	25% (5)	35% (7)	15% (3)	25% (5)
Tasmanian mothers	--	65% (13)	15% (3)	20% (4)
Tasmanian fathers	--	40% (8)	25% (5)	35% (7)
Mainland mothers	--	--	50% (14)	50% (14)
Mainland fathers	11% (3)	--	32% (9)	57% (16)

Table 5.6 : Parents' job

Parents	Home	Unskld	Semi. S	Skilled	Prof.
Iranian mothers	65% (13)	5% (1)	5% (1)	5% (1)	20% (4)
Iranian fathers	5% (1)	10% (2)	32% (6)	21% (4)	32% (6)
Total	70%	15%	37%	26%	52%
Tas. mothers	65% (13)	5% (1)	10% (2)	15% (3)	5% (1)
Tas. fathers	15% (3)	--	20% (4)	45% (9)	20% (4)
Total	80%	5%	30%	60%	25%
Mainland mothers	50% (14)	---	---	18% (5)	32% (9)
Mainland fathers	--	---	19% (5)	26% (7)	55% (15)
Total	50%	----	19%	44%	87%

As shown in Table 5.6 the majority of all mothers were home-maker. Thirty two percent (6) of Iranian fathers were semi skilled and thirty two percent (6) had professional jobs. In Tasmania, 45% (9) of fathers had skilled jobs, and 20% (4) were professionals. On mainland Australia 26% (7) had skilled jobs and 55% (15) had professional jobs. Three Tasmanian fathers were pensioners who were included under the category 'Home'. On mainland Australia, two fathers were self-employed, the job of one father was considered as skilled and another one as professional. The job of one father was unknown who were not included in the table. The majority of mothers in this study were home-makers and the majority of fathers had skilled and professional jobs.

5.2.2 Number of Children in the Family

As shown in Table 5.7, 50% (10) of Iranian families has at least three children, 60% (12) of Tasmanian families had at least three, and 77% (22) on mainland Australia had at least three children.

Table 5.7: Number of children in the family

No. of children	1	2	3	4	5	6	7	8	9	11
Iran family	20% (4)	5% (1)	25% (5)	10% (2)	15% (3)	10% (2)	--	5% (1)	5% (1)	5% (1)
Tasmania family	10% (2)	20% (4)	30% (6)	30% (6)	--	5% (1)	5% (1)	--	--	--
Mainland family	7% (2)	35% (10)	35% (10)	11% (3)	4% (1)	4% (1)	--	4% (1)	--	--

5.3 Mothers' Finding out About Ds

Mothers were asked when they found out that their children had Ds and who told them.

5.3.1 When Mothers Were Told About Diagnosis

In Iran, 45% (9) of mothers were told the first, second, or third day that the child was born, 35% (7) were told after weeks or months, 20% (4) were told when the child was between 1-2 years old. In Tasmania, 45% (9) of mothers were told the first day that the child was born, 5% (1) were told the second day, 25% (5) knew by looking at the child, 10% (2) were told between 2 to 6 weeks, 15% (3) had adopted the child. On mainland Australia, 64% (18) of mothers were told at the birth, 21% (6) in

the first and second day, 4% (1) after 6 weeks, 7% (2) knew by looking at the child, and 4% (1) had adopted the child.

5.3.2 Who Told Mothers

In Iran, 75% (15) of mothers were told by a doctor, 10% (2) by a nurse, 10% (2) by a friend, 5% (1) of mothers found out themselves. In Tasmania, 50% (10) of mothers were told by a doctor, 5% (1) by a social worker, 5% (1) by spouse, 25% (5) knew by looking at the child, 15% (3) had adopted the child. On mainland Australia 82% (23) percent of mothers were told by a doctor, 7% (2) by spouse, 7% (2) found out by looking at the child, 4 (1) percent had adopted the child.

5.3.3 How Mothers Were Told

In Iran, 25% (5) of mothers were told the child had Down syndrome, 45% (9) were told their child was 'mentally retarded or not normal', 5% (1) were told their child was a 'Mongol'. Twenty five percent (5) did not respond. In Tasmania, 55% (11) were told their child had Down syndrome, for 5% (1) the word, 'Mongol' was used, 25% (5) knew themselves and 15% (3) fifteen percent had adopted the child. Mothers in mainland Australia were not asked this question.

5.4 Mothers' reactions

In Iran, the reaction of mothers after finding out the diagnosis were mixed. Forty percent (8) cried and felt guilty, 20% (4) shocked and upset, 5% (1) rejected the child, 10% (2) accepted the child, 25% (5) did not answer. In Tasmania, 25% (5) cried, 50% (10) shocked and upset, 5% (1) rejected the child, and 5% (1) accepted the child. On mainland Australia⁷, 21% (6) cried, 57% (16) shocked and upset, 14% (4) grief and fear, 7% (2) hoped the child would die, and 18% (5) had no problems.

5.5 Mothers' Emotional and Social Problems

With regard to emotional problems, in Iran, 10% (2) reported that they were upset or could not accept the child, 65% (13) felt guilt and fear, and 25% (5) were worried. In Tasmania, 10% (2) could not accept the child, 45% (9) felt grief, 15% (3) were shocked, and 30% (6) stated they had adopted the child or had no problem. On mainland Australia⁸, 18% (5) felt grief, 11% (3) guilt and fear, 50% (14) shocked, 4% (1) could not believe the diagnosis, and 18% (5) had no problem.

With regard to social problems, in Iran, 65% (13) reported they had problems with relatives, other children, or members of the public, 15% (3) isolated the child in a room, 5% (1) of marriages ended in divorce, and 15% (3) reported they had no problem. In Tasmania, 45% (9) reported they had problems with family or members of the public, and 55% (11) reported they had no social problems. On mainland Australia, 14% (4) of mothers had social problems with family, and 29% (8) had problems with people in general. 57% (16) did not have social problems, or had adopted the child.

5.5.1 Perceived Impact on Mothers

Mothers were asked whether they felt any limitations in their lives due to having a child with Ds. In Iran, 20% (4) of mothers preferred not to take the child out in public, 20% (4) preferred not to socialise, 25% (5) did not reveal that their child had Ds, 10% (2) isolated the child in a room, 20% (4) reported no limitations, and 5% (1) did not respond. In Tasmania, 35% (7) of mothers felt limited in society, for example they felt they could not take the child to a restaurant, shop, or supermarket, and 20% (4) were tired of taking care of their child all the time. Forty five (9) percent did not feel any limitations to their lives. Mothers in mainland Australia were not asked this question.

5.5.2 Specific Family Needs

In Iran⁹ 45% (9) of mothers reported specific needs for their family such as acceptance of and love of the child by parents and grand parents, and information about Ds for parents. Twenty percent (4) reported specific needs for society such as acceptance and support by society, and changing attitudes of society. Forty percent (8) reported needs for services such as regular schools, early intervention programs, free dental care, community services which lead to a good living environment and staff care. Ten percent (2) expressed needs for professionals such as the way that specialists treat mothers could be better.

In Tasmania¹⁰, 55% (11) expressed specific needs which related to their families such as acceptance of the child and information about Ds, 25% (5) mentioned specific needs which related to society such as acceptance of and support by society, 35% (7) expressed specific needs for services such as early intervention programs, therapy programs, regular school, and respite care. Twenty percent (4) mentioned needs which relate to professionals such as a good doctor, good staff at school, and getting professionals involved.

On mainland Australia¹¹, 36% (10) of mothers expressed needs for their family such as acceptance of and love for the child with Ds by the family, accurate and correct information about Ds, and parent networks. Twenty one percent (6) mentioned needs for society such as acceptance and support by society. Seventy nine percent (22) expressed needs for services such as early intervention programs, speech and physio therapy, integration in school, and respite care. Four percent (1) mentioned needs which related to the attitudes of professionals and that doctors should not point out only the negatives.

5.6 Social Services

Social services include social services available to children, and support services available to mothers because of having a child with Ds.

5.6.1 Social Services For Children With Ds

In Iran, 100% (20) of mothers reported that nobody informed them what services were available to their children. This ratio for mothers in Tasmania was 45% (9) and for mothers on the Mainland Australia was 11% (3). Sixty five percent (13) of Iranian children had access to special schools. Of 35% (7) of children who did not have educational programs, 20% (4) were between the age of 4 to 8 years. Only 20% (4) of children had access to speech therapy. In Tasmania, 95% (19) of children attended special education schools, 5% (1) attended regular schools, and 95% (19) had access to therapy, 5% (1) did not have therapy. Twenty five (5) percent of mothers indicated problems in education, 20% (4) mentioned problems in therapy, 45% (9) reported other problems such as only five minutes of physio therapy, not being allowed to attend more than one center for early intervention programs, and not having the same access to services as children with Ds in an urban environment. On mainland Australia, 100% (28) of children had access to education, 71% (20) had access to health services. Twenty nine percent (8) of mothers reported that their children did not receive speech or physio therapy.

5.6.2 Support Services For Mothers

Forty percent (8) of mothers confronted problems such as not finding information about Down syndrome, not finding a right place for the child, no access into a regular school, long waiting lists and distant location of speech therapy, and health problems that their children had in winter time which resulted in decreased education. When mothers on mainland Australia were asked whether they were offered counselling or support as a mother of a child with Ds, 79% (22) answered that they had, and 21% (6) answered that they were not offered any counselling or support. Iranian and Tasmanian mothers were not asked this question.

5.7 Mothers' Perceptions

Mothers identified factors that determine the level of quality of life for their children.

5.7.1 Important Factors For Improvement

Mothers' perceptions about important factors for improving the quality of life of their children were classified under four headings: mothers, society, services, and professionals. In Iran¹², 35% (7) of mothers in the target group identified love and care of children by mothers, information about Ds, educational classes for pregnant mothers, and family allowance issues as important factors. Twenty percent (4) of mothers saw acceptance of children by society, and changing attitudes of society as important factors. Sixty percent (12) of mothers considered educational and therapy programs, such as being permitted to regular schools, being socialised with other children, and appropriate services in the community which lead to a good living conditions and meet the needs of children with Ds. Ten percent (2) of mothers rated the ways specialists treat mothers, and expected the professionals to treat them in a better way.

In Tasmania¹³, 35% (7) of mothers in the target group considered love and acceptance of children with Ds by mothers, information about Ds, and keeping parents together as issues of paramount important to the child's quality of life. Thirty percent (6) of mothers emphasised that love and acceptance of children with Ds by society, and changing the attitudes of society toward children with Ds are of special importance. Fifty percent (10) of mothers believed that educational and health programs such as regular schools for children with Ds, access to speech and physio therapy, early intervention programs, and meeting the medical needs of their children are important factors in improving in the quality of life of their children. Ten percent of mothers (2) reported that changing attitudes of professionals toward their children is of importance.

On mainland Australia¹⁴, 29% (8) of mothers reported that issues such as acceptance, love and support by mothers, the need to be positive, and the information about Ds to the importance. Sixty four percent (18) of mothers believed that issues such as acceptance and understanding by society including acceptance by peers and people, changing attitudes of society, opportunity for children with Ds to work, and other activities such as music, art, dance, and finally people misjudging about children with Ds, as important factors for improvement. Seventy five percent (21) of mothers emphasised that issues such as acceptance in regular schools, early intervention programs, good medical care, and better education to be important needs. Eleven percent (3) of mothers considered issues such as professionals' help, and that doctors needed to up- to-date their information about Ds, and to educate teachers and health workers about Down syndrome as important factors.

5.7.2 Important Factors Which May Lead to a Regression

In Iran¹¹, 35% (7) of mothers named issues such as unacceptance of the child by family, isolating the children, not having information about Ds, divorce of mothers because of the birth of the child, and finally if mothers and children are left alone without any service programs as important factors. Thirty percent (6) of mothers named issues which referred to society such as negative social attitudes, social stigma, and unacceptance of the child with Ds by society. Forty percent (8) of mothers rated factors which referred to services such as no educational programs for children after primary school, no early intervention programs, not being allowed to enter regular schools, no access to services, inappropriate public services in the community, and long waiting lists for therapy programs. Ten percent (2) of mothers named factors such as doctors do not give information about Ds to mothers, and the general information by doctors was that nothing can be done due to the child being with Ds. Ten percent (2) of mothers did not respond.

In Tasmania¹¹, 20% (4) of mothers considered issues such as divorce of mothers because of the child, to compare children with each other, not to push children for learning, and finally if mothers are not involved in the community as important factors. Thirty percent (6) of mothers reported issues such as negative attitudes of society, unacceptance of children with Ds by society, and isolation in small area as factors which led to a reduction in the quality of life of their children. Sixty five percent (13) of mothers believed issues such as going to special school, to cut services in early intervention programs, lack of integration in educational programs, medical problems including heart surgery and having colds for a long period influenced negatively the quality of life of their children. Ten percent (2) of mothers rated issues such as some professionals need to have updated education while some had poor expectations of the child with Ds.

On mainland Australia¹¹, 25% (7) of mothers reported that issues such as lack of acceptance and understanding the child with Ds, limiting the expectations on the child with Ds, low self esteem, labelling, treating children with Ds differently, not giving them chance to do everything as other children, being told their children with Ds cannot do something because of Ds, were important factors. Thirty nine percent (11) of mothers considered issues such as negative attitudes and unacceptance of society, lack of peer friendships, isolation, and segregation, people's preconceived ideas, people underestimating the ability of their children with Ds, people do not treat children with Ds like other children as key factors. Seventy five percent (21) of mothers reported issues such as lack of access to early intervention programs, lack of education and health care, services at token levels, denial of normal rights to health, no disability allowance, not enough speech services, institutionalising children with Ds, poor health care, and lack of teachers as important factors not pertinent to improvement. Eleven percent (3) of mothers considered issues such as doctors who think they know everything but they do not, professionals who refuse to accept

parents' points of view about Ds, and medical teams who demonstrate lack of interest towards children with Ds, as important factors which may affect improvement.

5.8 The Extent of and Satisfaction With Services

Mothers were asked about the extent of available and relevant social services. In Iran, 70% (14) of mothers believed that social services are not available for all children with Ds.

In Tasmania, 75% (15) and mainland Australia 92% (26) of mothers believed that social services are not available for all children with Ds.

When mothers were asked about their satisfaction with social services, 65% (13) of Iranian mothers, 45% (9) of Tasmanian mothers and 61% (17) of mothers living on mainland Australia reported that they were not satisfied with social services.

In the next chapter, chapter 6, findings from case studies and interviews in Iran, case studies and interviews in Tasmania, and the mail survey on the Australian mainland will be discussed.

Chapter 6

Discussion and Conclusions

This chapter consists of two parts: Part A and Part B

6.1 Part A Overview

The purpose of this section is to critically analyse and discuss the findings from the case studies and single interviews developed in Iran, Tasmania, and the mail survey on the Australian mainland. Education and health issues of children with Ds arising from the research findings will be critically assessed, and aspects of the current literature will be reviewed in the light of the findings.

6.2 Family

Since family is the oldest and most fundamental social institution, it serves as a profound influence upon the life of the children.

6.2.1 Family Structure

The majority of mothers in this study were between 30-49 years of age who were primarily home-makers, thus having greater opportunity to allocate particular attention to their children. Their level of education proved a key factor in helping in them to have a better understanding of their situation. In addition to having a child with Ds, most mothers also experienced raising a child without Ds which indicated that they were well aware of the differences between children.

6.2.2 Number of Children in the Family

The study indicated that when a child with Ds is the first child, mothers experienced more difficulties as compared to mothers who already had a child or children when the child with Ds was born whereas this may be true for all mothers experiencing their first child, having a child with Ds is experienced as something

quite different. For example, the mother in interview # 1 said: "I am pregnant now because we wanted to have another child". This mother felt that she had failed to have a healthy child and wanted to have another child. Some mothers wanted to have another child in order to have a sibling for the child with Ds. As indicated in interview #2 "We also believe that we should have another child in order not to leave our son alone". In fact, siblings play an important role for the child with Ds. In interview # 7 the mother concluded: "My children and my husband spend considerable time teaching her [the child with Ds] different things".

Most mothers who had other children were glad that the child with Ds was not the only child in the family and comments indicated other underlying reasons such as, "... now that we have other children people know that we have also succeeded" (#23).

6.3 Mothers Finding out About Ds

Mothers were asked when they found out about diagnosis and who told them first.

6.3.1 When Mothers Were Told About Diagnosis

The majority of mothers in Australia (33), were told within the first three days, however, there were mothers (3) who were told between 2 to 6 weeks. The majority of Iranian mothers 55% (11), were told after weeks or months, or even when the child was two years old. During this period of time mothers knew that their children were not progressing like other children of the same age, but were unable to realise the cause. Clearly, when a significant diagnosis such as Ds is delayed, the child loses an opportunity for intervention and appropriate support.

6.3.2 Who Told Mothers

A majority of mothers in Iran 75% (15), and a majority of Australian mothers 68% (33), were told by a doctor which indicated doctors do play an important role in informing mothers about the diagnosis.

6.3.3 How Mothers Were Told

Most Australian doctors used the term 'Ds', whereas Iranian doctors used the term 'Mongol', or 'mentally retarded'. For example in Iran one mother said, "The doctor told me that I should not waste much time on him and must not expect much of him, only feed him" (# 5). Another mother stated "... the doctor told me nothing can be done, he is not normal" (#14), or "Your child is Mongol" (#17).

Although Australian doctors used the word 'Down syndrome', many mothers reported a negative experience which gave them a feeling that something unpleasant had happened. For example: "I saw that the nurses were whispering to each other and one of the nurses whispered to the doctor. All of the nurses went out of the room" (# 23), or "I saw a nurse had a short talk with the doctor. Then they disappeared very quickly" (#29). One child suffered complications at birth as can be seen with the following memory "My child was also diagnosed with acute leukemia besides having Ds, and we were told he would live for a few weeks... that was a shock but he did survive" (#34).

6.4 Mothers' Reactions

Mothers' reported reactions following their child's diagnosis were varied but included crying, being shocked and upset. Some had feelings of guilt, grief and fear, rejecting the child or hoping that the child would die. This raises questions such as:

- Why do mothers have negative reactions and emotional feelings?
- Are these feelings to be expected?
- Are these feelings permanent?

One way to consider these negative feelings is in relation to the kind of information that mothers repeatedly received. For example one mother noted: "One doctor suggested that we did have choices, ... to have him adopted. But we never considered that as an option" (# 34). Most mothers were often informed of their child's condition in a negative way with negative attitudes which implied that the mother had not succeeded in having a healthy child; that the child would not be able to have a normal life but would be dependent on the mother and/or the child had a disability. This research generated examples that mothers gradually experienced their situation of being not as bad as they had thought in the beginning. For example, as interview # 25 indicated, "I had problems for the first four months. It took me eight months to cope with the problem ... My husband said if we do not keep her eventually it splits us ... Now it has made us a very strong couple". Another mother said she was depressed only in the beginning "... I was quite depressed the first six months ... my other children love her very much, and I am very lucky" (# 35).

Unlike many professionals such as Cunningham and Sloper (1983), Hornby (1991), and Stratford (1989) who asserted that the theme of 'parental guilt' is ancient and a natural reaction to the situation, the results from this study revealed that since mothers were informed of their child's condition in such a negative way, that stimulated unusually strong negative feelings. No professional said they were happy at the birth of a child with Ds and their attitudes suggested that overall they were sorry for the mother. In no case did professionals ever congratulate the mother in the same fashion that they congratulated mothers of children born without a disability, but instead projected attitudes of sorrow and pity. Thus, it is the position in this research that mothers' negative reactions are by and large due to the negative way that professionals inform and treat mothers. Some health professionals even recommended parents give their child up for adoption. Mothers may choose adoption as a solution for their feelings of conflict and the crisis they confront, but after the crisis they may regret their decision. For example, with one Australian

mother, "We talked to the social worker in the hospital. Then we decided to have him adopted. We left him in the hospital, but after two weeks we changed our minds" (# 22). This example indicates that in Australia, many professionals often urge mothers to give their child with Ds up for adoption or to institutionalise the child. However, in Iran, professionals only indicated that the child is 'mentally retarded' without further suggestions, because adoption and institutionalisation take place only under rare circumstances.

Mothers who have adopted a child with Ds do not have the same emotional feelings or negative reactions. They reported that they were not treated negatively by professionals. Moreover these mothers were content with simply helping the child. For example one mother reported, "We wanted to adopt a child with special needs and a child with Ds was the first one available" (# 33) while another mother stated: Everybody in our place said how marvellous it was that we took care of this child (# 40).

Professionals like Cunningham and Sloper (1983) stated that some parents wish that their child with Ds was dead. In this study there were only two out of twenty mothers who wished that their child with Ds would die. This study, suggests that mothers' extreme negative reactions toward their children may be negated if professionals changed the traditional way of pointing out the negatives, and instead emphasised the potential and possibilities of a child with Ds.

6.5 Mothers' Emotional and Social Problems

Rejecting and not accepting the child, and wishing the child would die were considered to be severe example of mothers' emotional problems. Examples of non-acceptance of the child are: "After one year I still can not accept my situation" (# 1), or "After five years I still have emotional and social problems, I still hesitate to take her out" (# 30). Or "... I do not like being around Ds children" (# 38).

Mothers in this study experienced social problems such as not being understood by family and relatives, and being upset by the reactions of professionals in the health system, staff in schools, neighbours, or the public. These experiences were not related to culture or location. The study findings supported the literature that the pessimistic reactions of professionals result in negative feelings and lack of acceptance of the child by the mother.

Some mothers reported feeling tired because of the time that was required to be allocated for their child. Likewise, often mothers preferred not to go to public places such as restaurants or supermarkets because of the negative attitudes of people.

6.5.1 Perceived Impact on Mothers

Many mothers felt they had some restrictions placed upon them as a result of having a child with Ds. Since people in society often have negative attitudes toward children with Ds, many mothers preferred not to socialise outside the family. For example: "People have always had pity and that does not help" (# 23), or "... some people cannot accept anybody who is different, some people look at him very strangely, and reflect the negative attitudes of society" (# 38). These examples provide some indication that society in general limits mothers of children with Ds.

6.5.2 Specific Family Needs

Mothers commented that the most important need of children with Ds is acceptance of and love by parents and acceptance within society. Mothers emphasised the need for family stability, since some parents divorce when they find out that their child had Ds. For example: "My husband and I had a difficult time and were feeling very guilty. Later, my husband was not interested in coming home on time. Finally we decided to get divorced. My child split my husband and I" (# 3), or "My child is not living with me now... (# 30).

All mothers mentioned needs related to society such as acceptance of and love the child by society, and the need to/the change attitudes of society. Their needs include access to appropriate social services, such as therapy programs, regular school, and respite care.

In terms of health many mothers expressed that their children were sensitive to cold weather, suffered frequent colds, are often on medication (#24), and suffer regular chest infections (29). This is one health problem for which there has been no solution yet. One mother commented "The only thing is that my child usually has colds for a long period and has to take antibiotics which may be a factor for regression" (# 30).

Finally, Iranian mothers expressed the need for a family allowance as there is no Iranian equivalent to the Australian family allowance program. In summary, there is a need for society in general to change the negative attitudes toward children with Ds which may also affect some mothers' adverse reactions and lead to acceptance of their child.

6.6 Social Services

Social services are discussed in two sections: social services available to children with Ds, and support services available to mothers.

6.6.1 Social Services For Children With Ds

Iranian children with Ds do not receive services such as early intervention and they are admitted to exceptional schools which also provide places for children with behavioural problems. There was no educational programs for 20% (4) of children between the age of 4 to 8 years.

In Tasmania, mothers in general were not satisfied with sending their children with Ds to special schools because they believed they experienced greater progression in a regular school. For example:

"... about schooling, I think it does not reach all children to the best of their ability... The Education Department limits them to do a lot of painting, swimming, or bike riding. These are important but they are limiting children. Whereas these children can achieve more. ... The education Department concentrate on everything else except the education. ... In my case, going to a special school is a regression" (# 38).

This kind of research supports work by Macy and Carter (in Casey, 1994) who found there to be "... improved performance of mildly retarded children in the normal classroom settings" (p.24). These case studies support the 'power of imitation' and suggest that children with Ds should not be integrated with children who have behavioural problems, unlike the current practice in Iran and Tasmania.

In Northern Tasmania, when children with Ds turned seven years they had to leave the family and live in Location E or Location F for education because they were not accepted in local schools. There are still children with Ds who are not living with their families. One mother, living in a rural area complained about visiting her son only on weekends because her son attends school located in a city. According to the principal of the school, the school cannot provide daily transportation for her son because his house is in a rural area and far from the city. According to the former Health Minister (*The Examiner*, 1-20-1996, p.13) "It is hard to justify area B as a remote area because it is less than 30 minutes drive to the city on a well maintained highway". This mother said the problem is that the principal of the school at area B refused to register her son at the local school, so the only choice is Location F. This case indicated that educational services are not accessible for a child with Ds and this child was deprived of living in their home environment.

In Tasmania, it has been only recently that children may attend regular schools. However, it depends on parents' efforts to convince the principal of the school and other parents. For example: "When he went to the local school I was not happy because they were segregating him. It was a very small local school with 45 children. My son had a lack of confidence. I changed his school. I had to talk to many staff

and took him to a school which is 45 minutes away from where I live" (# 28).

However, mothers have to put efforts to make staff understand that their children are capable of learning. One mother tried to convince staff to admit her son in a regular school as well as talking to parents. Finally she succeeded, but at the end of year she was advised by the school that it was better for her son to attend special school.

"... sometimes headmasters do not like the idea of integration and the staff at ordinary schools discuss that these children are too much of a problem and we have to educate them a little bit to the fact that these kids are not that bad" (# 37).

The following extract provides a possible reason why some mothers are not happy with the education services.

Some staff need to be aware and trained at school because they are a little negative. For example, last week one of the staff told me now she realises that these children are not dumb. So, they expected these children not to be able to read or to write. In fact, they do not have the experience that we assume (# 34).

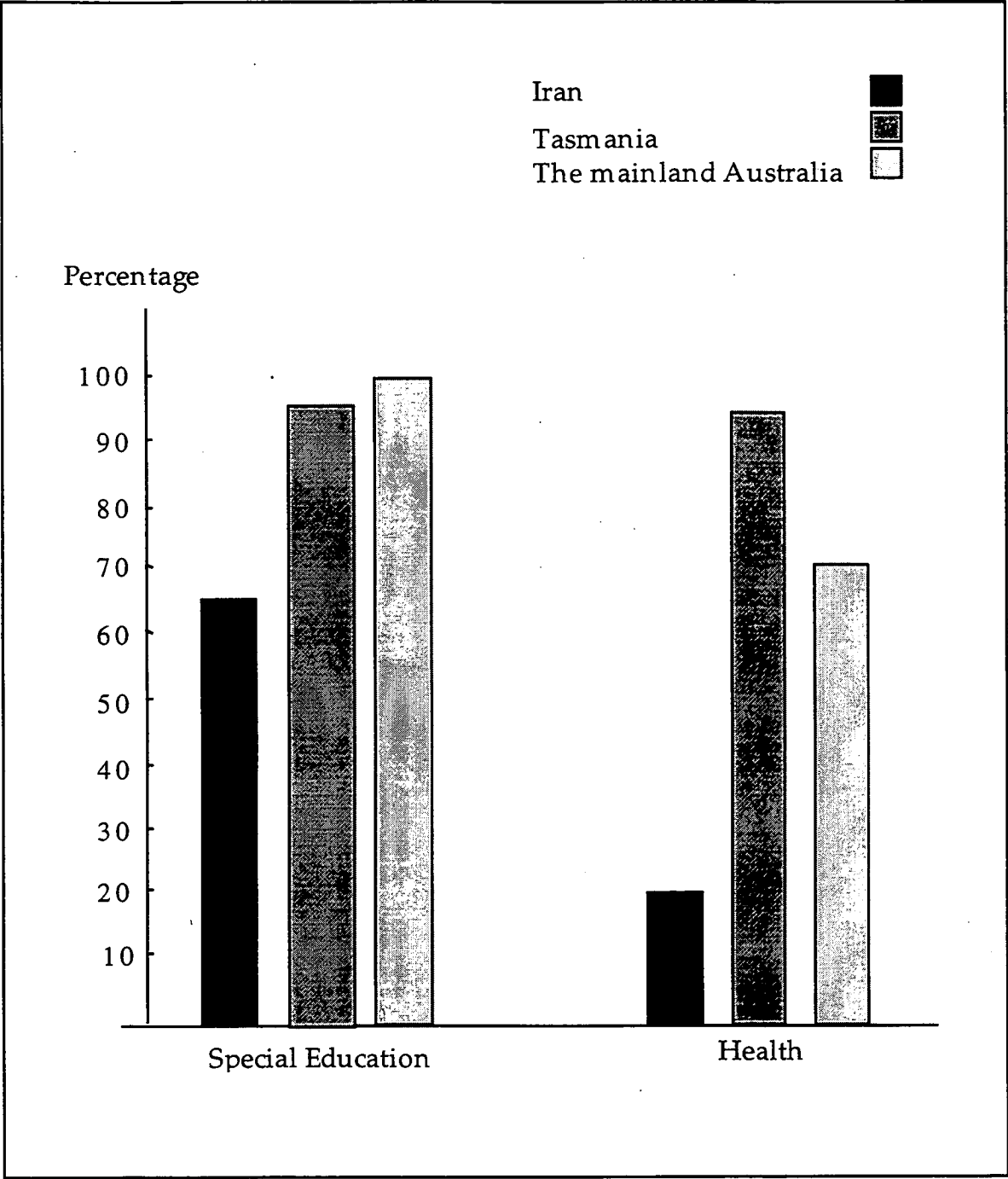
In Iran, only 20% (4) of children had access to speech therapy and depended on mothers' efforts to look for the program. In Tasmania, although there are limited services available for children, mothers identified problems such as long waiting lists for occupational therapy or no regular occupational therapy and that it was difficult to have occupational therapists in Tasmania because the Health Department does not pay enough. Another mother said that occupational therapy program was not adequate (#25), and a mother living in a rural area reported that physio therapy programs had been reduced (#30). One mother named problems in occupational therapy and said: "But I am aware of health service limitations which limit my child ... (#31).

Mothers are aware of the lack of services and believe that education and health services are not accessible, adequate, or appropriate for their children. Moreover, services in locations D and E were not well prepared to present to children with Ds.

Children with Ds need services that are not available to them, and they are deprived of their needs which affects their quality of life. According to Brown et al. (1988) quality of life is the discrepancy between a person's achieved and unmet needs and desires. The study revealed that children with Ds have unmet needs in the areas of health and education and they have a low quality of life in relation to receiving social services. A comparison of mothers' assessment of the quality and comment of social service programs, indicates that social services in Iran in particular are limited for children with Ds (Graph 6.1). The Iranian Ministry of Education could play an important role in:

- changing the present educational system of pass or fail toward a system of not limiting children for further education,
- re-educating of professionals and educators and staff in schools about Down syndrome, and
- providing children with Ds with early intervention programs.

Even though these limitations are not evident in Australia, there is a need to review the policy of Australian education programs by the State Departments of Education.



Graph 6.1: A comparison of mothers' assessment of the adequacy and of social service programs.

6.6.2 Support Services For Mothers

One of the important needs expressed by mothers was to be provided with information about the availability of services. An example of a comment by an Iranian mother was: "The doctor only said: nothing can be done" (# 14).

Mothers believed that it was difficult to find correct information about Down syndrome and medical students were often misinformed by professionals when learning about Down syndrome. Clearly there is clearly a gap between what parents need and what professionals think.

The contact that I had in hospital was a lady from Northern Support. I had to leave a message three times, before I got hold of her. She gave me a book on brain injury and said that she did not know anything about Ds ... although Ds is a common disability, most doctors do not seem to know about it. General Practitioners do not have enough information ... I know of a mother with a child with DS who attended a class where a doctor was talking about Ds to medical students and some of his information about Ds was totally incorrect. This mother did not have any opportunity to correct the doctor because she was asked not to (# 35).

Tasmanian mothers got most information about Down syndrome and the availability of services through other mothers who have a child with Ds. A mother said: "All support is through parents who are not professionals. Work is done through non professional groups. This is a big hole. Parents need professionals to be involved" (# 25). Another mother said, "At hospital I was not given any information, but I got information through other mothers" (# 21). Or, "The only booklet given to me by support group was out of date with old pictures" (# 24). One mother said that how hard it was for her to find out about available services(# 35).

Professionals advised one mother to leave her child in a center. "My paediatrician told me about Location G" (# 36). This mother was possibly

misinformed by the paediatrician's lack of knowledge about Ds. The last comment regarding Location G referred to a special school for children with severe disabilities who lived away from their families.

On mainland Australia, it appears that mothers got information about Down syndrome and the availability of services from other mothers, Down syndrome Associations, or health professionals, such as paediatricians, nurses, or social workers. However, there were mothers, about 10%, who were not told at all. The study revealed that there are mothers in Iran and Australia who were not informed about the availability of services when they were told that they had a child with Ds.

Mothers reported that their children confronted serious health problems because doctors did not realise health needs of children with Ds (#23 & 35). Moreover, as one mother said, some professionals do not realise what, with occupational therapy and speech therapy, is achieved:

... if a 4-year old child with Ds is still not talking very well, a paediatrician may say: Well , that's the way it is, rather than saying: you need to see a speech therapist (# 25).

Neither Iranian nor Tasmanian mothers in this study were offered counselling, whereas 79% (22) of mothers on the mainland Australia had counselling by either representatives from DS Associations or hospital staff such as a paediatrician, a social worker, or nurse. However, their specific needs included recognition and respect for the expertise that mothers develop about their own child, receiving unbiased services, and reinforcement of their parents' worth as by professionals.

Professionals' lack of knowledge about Down syndrome, negative attitudes of professionals and people in society, and the current practices for mothers with a child with Ds, are major barriers for children with Ds and their families. There is a need for the Australian Ministry of Health to review health programs with more emphasis on rural areas, and plan for increasing paediatric knowledge in the field of Ds through educational seminars. It is suggested that Iranian Ministry of Health could play an important role addressing these barriers by:

- increasing health professionals' knowledge in the field of Ds through educational seminars,
- providing hospitals with a Down syndrome package for mothers of babies with Ds, and referring them to early intervention programs.

6.7 Mothers' Perceptions

Factors identified by mothers that determine the level of quality of life for their children were grouped under four headings: mothers, society, services, and professionals. Although professionals are a group of people within society, the influence that they have on making judgements about Ds is so important that they have been considered separately.

6.7.1 Important factors for improvement

The majority of mothers (60% in Iran, 50% in Tasmania, 75% on mainland Australia) mentioned that social services are the most important factor. Children with Ds should be integrated into regular classrooms. As one mother said:

If they are integrated back into normal schools of course they will not be as quick as other children or as bright as other children, but the rest of society will learn to live with these children rather than not to know them. So, they need to be integrated into the system rather than locked away and to be isolated... They are not in special needs society but normal society. So, they should be learning to do everything with everybody else (# 37).

One mother said:

Through his school I got the information that in Tasmania he would not go to a normal school and there are special schools. I took him to Location F. His recognition of words, the words he could write, his speech have all gone back. That's one thing that I think the Education Department should be really asked about (# 38).

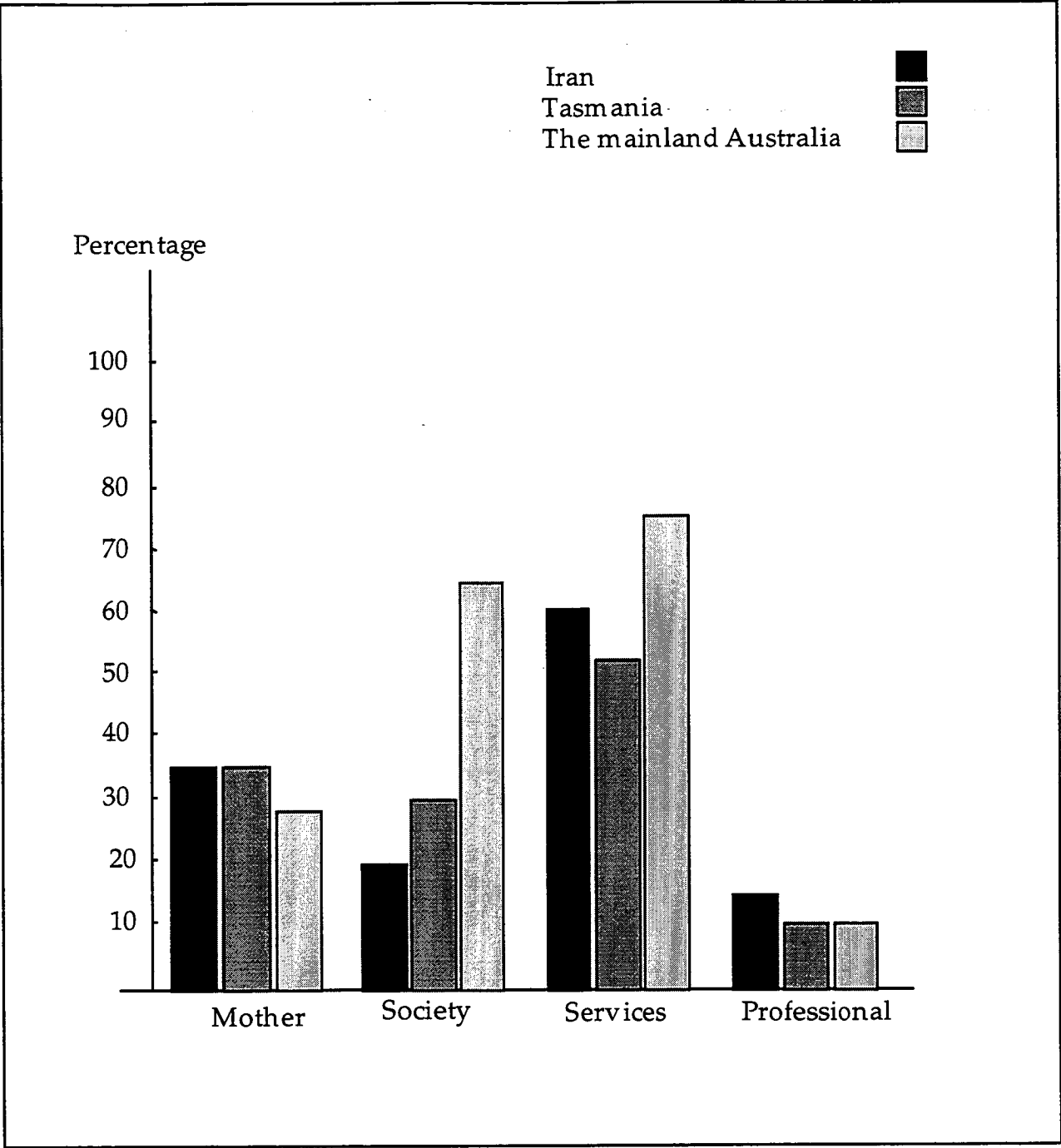
Mothers on mainland Australia added that opportunities should be given to children to reach their full potential and more aide hours should be offered at school. The second most important factor for both Iranian and Tasmanian mothers, was love

and acceptance of the child by the family, and for mothers on the Mainland Australia, love and acceptance of the child by society. The third most important factor for Iranian mothers, and Tasmanian mothers was love and acceptance of the child by the society. Mothers on mainland Australia mentioned love and acceptance of the child by family as the third factor.

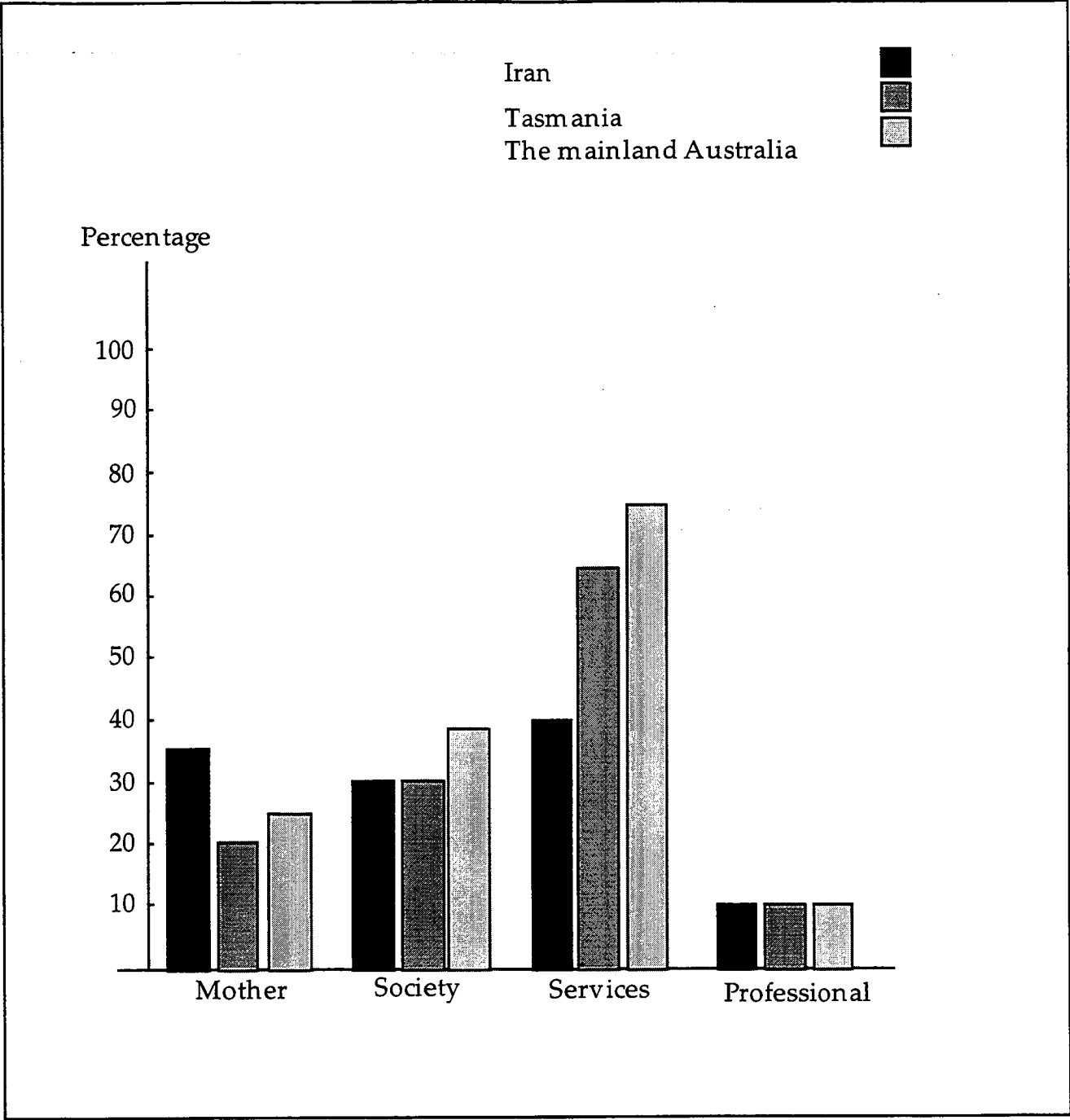
All mothers mentioned professionals' attitudes as the most important factor. Most mothers gradually realised that their situation was not as bad as they had originally felt, and that professionals could be wrong too. Graph 6.2 compares mothers' perceptions of areas needing improvement in Iran, Tasmania and the mainland Australia.

6.7.2 Important Factors Which May Lead to a Regression

The majority of mothers in Tasmania and mainland Australia, and a large proportion of Iranian mothers mentioned the lack of appropriate services as the most important factor which may lead to a regression in the quality of life of their children. Lack of appropriate education and health services limit children with Ds and hinder their improvement. The second important factor for Iranian mothers was rejection and unacceptance of the child by the mother, and for Tasmanian mothers and mothers on mainland Australia, was society's attitudes. Iranian mothers, considered society's attitudes as the third factor while Tasmanian mothers and mothers on the Mainland Australia considered lack of family support and other family issues as the third factor. All mothers considered professionals' negative and unhelpful attitudes as the fourth important factor which may influence regression in the quality of life of their children (Graph 6.3). Significant factors were inappropriate services and the negative attitudes of society because society can influence the attitudes of mothers and professionals.



Graph 6.2: A comparison of mothers' perceptions of areas needing improvement



Graph 6.3: A comparison of mothers' perceptions who believe that certain factors lead to a regression in the child.

This study suggests that the quality of life of children with Ds could be improved if all children with Ds are provided with appropriate, adequate, and accessible health and educational programs. There is a need for the Ministries of Health and Education, in both Australia and Iran, to have a closer cooperation with each other to review their policy of service programs which lead towards making children with Ds independent as much as possible.

6.8 The Extent of and Satisfaction With Social Services

Social services in Iran are limited and difficult to access unless mothers and professionals have great determination. An example of the limited knowledge of mothers was shown when a mother stated that: "services are adequate because there are exceptional schools".

Tasmanian mothers believed that advice to use the services is not routine but rather is left to the discretion of mothers. However, mothers have to put much energy and effort into finding out about and accessing available services. In addition, there is little or no access to services in rural areas. Most Tasmanian mothers expressed barriers to and limitations of services. On mainland Australia, mothers believed that social services did not reach all children with Ds due to factors such as the lack of services, long waiting lists for services, parents' lack of knowledge and lack of up-to-date information.

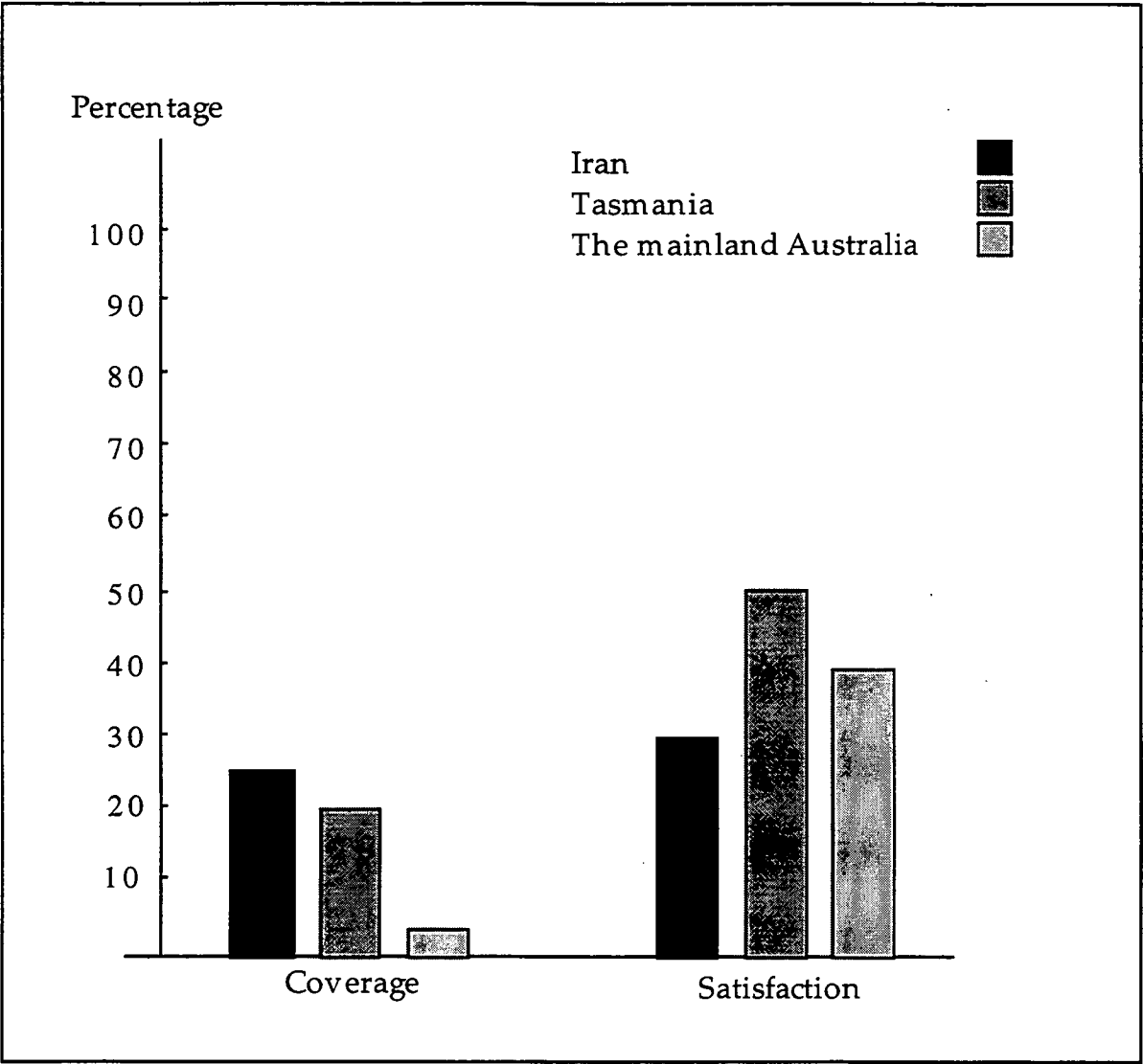
Iranian mothers were generally not satisfied with services because there are no special services for children with Ds. Tasmanian mothers are not satisfied with services because there are not many services and access to even limited programs in rural areas. With regard to the percentage of mothers in Tasmania, (50%) who were satisfied with services and considering the negative relation between location D and E, it seems that mothers who were attending location D were conservative and did

not disclose their dissatisfaction with services. This may be a reason for high percentage of satisfaction with social services in Tasmania.

On mainland Australia, over half of the mothers said that they were not satisfied with social services due to the lack of educational and health service programs, such as no speech or motor therapy, and the fact that the Department of Education was extremely unsupportive regarding integration into mainstream schools. A small number of mothers considered that: social services were under staffed, the NSW Department of Education left a lot to be desired, there was a need for more speech therapy, and better educational quality for children with Ds was needed.

On the whole, neither Iranian nor Australian mothers were satisfied with social services for their children with Ds (Graph 6.4). There is a need for Australian Departments of Health and Education, in each state, to review their programs.

Suggestions and solutions related to improvement in housing or employment were not included because they were not relevant to the aim of this study, and remain the scope of further research.



Graph 6.4: A comparison of the extent to which mothers expressed satisfaction with social services

6.9 Part B Overview

In this part, the summary and conclusions of the study are presented. This includes ideas to redress deficiencies in the present social service programs for children with Ds and their families. Part B concludes with suggestions for further research.

6.10 Summary of the Study

The focus of this study was the experiences of mothers of children with Ds and the provision of social services for their children and their families. Children with Ds have a range of physical and intellectual differences. This study examined the living conditions and quality of life of children with Ds based on mothers' experiences about social services. For the purpose of this study, the areas of health and education were selected as social services.

The nature of Down syndrome and its physical and intellectual effects were discussed, and the literature pertaining to social services was reviewed. The theory of normalisation and the social perspective of quality of life were provided as the theoretical frameworks. The key terms of: disability, Down syndrome, and social services, used through out the study, were defined. A review of the literature indicated that there is a gap between policy and practice, and although in Australia, early intervention and school age education are the constitutional responsibilities of the state government, a significant number of children with a disability do not have access to early intervention and education, especially in rural areas. With regard to society, the attitudes of society are not positive towards children with Ds and there are still children who are segregated from society. Also, there is a gap between what mothers of a child with Ds need and what professionals think mothers with a child with Ds need.

The problem relates to a real population group, who do not have the same rights as other children. Laws do not protect them from being killed before they are born because they are supposed, from the medical point of view, to have an inherently low quality of life. The literature indicated that there is a relationship between social services and the living conditions of these children. It suggested that the quality of life of children with Ds, their actual living conditions and their unmet needs should be examined.

Due to the nature of the problem, a qualitative, interpretive approach was adopted through the use of case studies, interviews and survey methods to produce practical solutions to the problem. The sample consisted of 68 mothers of children with Ds, who experienced the difficulties of raising their children. Data were coded by NUDIST to produce the headings: family, services, mothers' perceptions, and satisfaction with services. Descriptive analysis indicated four main areas determining the living conditions of children with Ds and their unmet needs.

Three specific questions guided this study. This summary of the findings is presented under three headings in response to the research questions.

- 1- Factors influencing a mother's perception of social services provided for her child with Ds.
- 2- Critical factors determining the level of quality of life of children with Ds as perceived by their mothers.
- 3- Conclusions that can be drawn from an examination of the lived experiences of Australian and Iranian mothers of children Ds.

Findings of the study indicated that:

- social services are not accessible, adequate, or appropriate in terms of problems such as long waiting lists, travelling to the city to receive services, not being allowed to attend regular school, and the frequency of services.
- professionals' lack of accurate information on Down syndrome, and the negative attitudes of society towards children with Ds and their families

are barriers to their problem.

With regard to education, on one hand, children with Ds have been or still are in special schools and are deprived of normal schooling. On the other hand there has been a tremendous positive change for children with Ds which indicates that the outcome of planning for improvement of the life of these children is positive, the children are capable of learning, and they are ready to assume responsibility in the society. Students with Ds should not be segregated in special schools as there will not be a special society for them in their adulthood. It is not surprising if students with Ds seem to have adjustment problems when they finish special school and come back to society, where other people do not know how to treat them. With regard to health, although there have been health programs which could affect the life of children positively, these programs are not available to all children.

Mothers emphasised factors determining the level of quality of life of their children. Appropriate social services were expressed to be the first important factors. The negative attitudes of society toward children with Ds was considered to be the second important factor. Children with Ds should have the right to live a normal life as much as possible. They should not be isolated because of having Ds. To separate children with Ds from other children results in social isolation and isolation does not have a positive outcome. In contrast, having a fulfilling social life for children with Ds should be emphasised.

Children with Ds learn effectively from observation and imitation of others. It is important that these children socialise with other children because the experience in elementary school is a base to prepare for a vibrant social life within society. Issues in relation to family including love and acceptance by the mother was the third important factor. The information that mother may receive about social services and facts about Down syndrome influences a mother's acceptance or rejection of her child. Finally, changing the attitudes of education and health professionals was considered to be the fourth important factor.

Mothers experienced that emotional problems after diagnosis about Down syndrome are not natural, real, or permanent, and it depends on how mothers are treated by professionals, society, and family.

6.11 Conclusion of the study

The findings of the study revealed that mothers of children with Ds considered there are major barriers preventing children with Ds from achieving a normal life. These barriers include the negative attitudes of health and education professionals; a lack of accurate information about Down syndrome; inappropriate social services; the current practice of informing mothers about their child's diagnosis; and difficulty in accessing information about Down syndrome and social services.

Mothers believed that appropriate social services is the first important issue for their children. Professionals, especially health professionals need to reconsider the way in which they inform a mother that her child has been born with Ds and, rather than project attitudes of sorrow and pity, they should congratulate the mother in the same fashion that they congratulate mothers of children born without Ds. At the same time, they must be honest and inform the mother of all available services to children with Ds and stress the need for early intervention programs from the very beginning. Although it is important that mothers of children born with Ds are informed quickly and honestly of the situation, mothers also need the chance to recover from delivery, and therefore, doctors must be sensitive enough to recognise the right time to inform the mother. Giving love to the child in the protective atmosphere of the home is of paramount importance. While raising a child in the home environment is preferred to institutions, there are centers in the two countries, Iran and Australia, where children are segregated from parents.

As a result of this study, it is suggested that there is a need for a new understanding and a new look at Ds, re-education of professionals and up-to-date information about Ds, for health and educational professionals, and society in

general. Clearly, the range and quality of social service programs offered by authorities in the Ministries of Health and Education in both Australia and Iran needs to be reviewed.

The conclusion drawn from the examination of experiences of mothers in Australia and Iran indicate that contrary to the literature, mothers' emotional problems are not natural feelings and could be prevented if professionals changed the traditional way of pointing out the negatives, and instead, emphasised the potential and possibilities of a child with Ds. Moreover, when a child with Ds is the first child, mothers experience more difficulties than mothers who already had a child or children when the child with Ds was born. The result of the literature research generated a background report for the Australian and Iranian Ministries of Health and Education with the intention of contributing to an improved quality of life for children with Ds.

6.12 Areas For Further Research

The study has indicated that there is a need for further research in the following areas:

- Professionals' perceptions of Down syndrome and mothers of a child with Ds.
- The effects of recreation and leisure programs for children with Ds.
- Employment and housing for students with Ds after completion of education.

Footnotes

1- Since the researcher has 20 years of experience with children with Ds and their families, as a social worker in Iran, and as a mother of a child with Ds, this study was conducted in both Iran and Australia specifically with the aim of improving the quality of life for Iranian children with Ds.

2- The researcher established the first Down syndrome Association in Iran in 1997.

3- Dolphin human therapy may not be seen to be related to the study, but what has been done as a treatment for children with Ds in the literature are presented.

4- The following information about the progress of children who use vitamin supplementation or MSB+ with piracetam, and NutriVene D supplements have been obtained through an email system called, the Down Syndrome listserv. This system, DOWN-SYN@VM1.NODAK.EDU, was started in the autumn of 1993 by Bill McGarry in the USA for the purpose of sharing information between parents and professionals. MSB+ is a mixture of vitamins, amino acids, and enzymes which target essential nutrients missing from the biochemical make up of people with DS (Email, 11-12-1995). Mothers state that this information is non-scientific, but based on their observations of their children. Brief descriptions of some of these children are given below.

Child's name: A

Date of Birth: 5-6-1988

Taking MSB+ without piracetam since 5-15-1995

Started piracetam since 6-16-1995

Result: As of 6-26-1995, child is more aware of his surroundings, improved sentence structure.

Child's name: B

Date of Birth: 7-18-1993

Taking vitamin since 3-1995 without MSB+ or piracetam

Result: PT has commented on concentration and fine motor skills since beginning vitamins.

Child's name: C

Date of Birth : 1-23-1989

Started MSB+ without piracetam on 6-3-1995

Result: Much better appetite. Speech is improving.

5- Child's name: D

Date of Birth: 1992

Started NutriVene D Supplements in 1996 and continuing in 1999

Results: Increase in speech, and increase of skills

6- NUDIST, a software system, is based on code-and-retrieve facility and was developed by Tom and Lyn Richards of La Trobe University. It stands for Non-numerical Unstructured Data Indexing, Searching and Theorising.

7- Australian mothers reported their complete reactions, and some of them named more than one reaction.

- 8- Australian mothers reported their complete emotional problems and some of them reported more than one emotional problem.
- 9- During interview mothers were provided with an opportunity to express their complete needs, and some of them reported more than one category.
- 10- During interview mothers were provided with an opportunity to express their complete needs, and some of them reported more than one category.
- 11- Mothers had the option of reporting more than one category.
- 12- Iranian mothers were provided with an open question to express their experience, and some of them reported more than one category.
- 13- Tasmanian mothers were provided with an open question to express their experience, and some of them reported more than one category.
- 14- Mothers on mainland Australia were provided with an open question to express their experience, and some of them reported more than one category.

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E-mail 1995a

Sender: Down Syndrome <DOWN-SYN@VM1.NODAK.EDU>

E-mail 1995b

Sender: Down Syndrome <DOWN-SYN@VM1.NODAK.EDU>

E-mail 1995c

Sender: Down Syndrome <DOWN-SYN@VM1.NODAK.EDU>

E-mail 1995d

Sender: Down Syndrome <DOWN-SYN@VM1.NODAK.EDU>

E-mail 1995e

Sender: Down Syndrome <DOWN-SYN@VM1.NODAK.EDU>

E-mail 1995f

Sender: Down Syndrome <DOWN-SYN@VM1.NODAK.EDU>

E-mail 1996

Sender: Down Syndrome <DOWN-SYN@VM1.NODAK.EDU>

E-mail 1999

Sender: Down Syndrome <DOWN-SYN@VM1.NODAK.EDU>

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APPENDIX A

Down Syndrome Medicine Checklist Compiled by the National Down Syndrome Congress Center 1994-5 Neonatal Through Adult

I) Neonatal period (birth - two months)

A. History

1. Parental concerns
2. Feeding pattern
3. Stooling pattern

B. Physical examination

1. Complete general physical and neurological examination
2. Plot height and weight on Down syndrome growth chart
3. Look for signs of congenital heart disease such as cyanosis, irregular heart rate, or heart murmur
4. Careful examination for otitis media and cataracts
5. Screen hearing

C. Lab

1. Karyotype
2. Thyroid function (THS)
3. Echocardiogram (SBE)
4. Auditory brainstem response (ABR)

D. Consultation

1. Cardiology
2. Genetic

E. Recommendations

1. A follow-up appointment at a Down syndrome center
2. Parent and education support by referral to local parent support group and the National Down Syndrome Congress
3. Referral to infant education program

II) Infancy (2 months - 12 months)

A. History

1. Review parental concerns

Appendix A continued

2. Review medical history, especially in relation to otitis media and constipation

B. Physical examination

1. General physical and neurological examination
2. Plot parameters on Down syndrome growth chart

C. Lab

1. Audiology assessment
2. Thyroid screening that includes T4 and TSH at one year of age

D. Consultation

1. Cardiology
2. Infant developmental specialist or team of occupational therapist, physical therapist, and speech and language therapist
3. Ophthalmology
4. Nutritional where indicated

E. Recommendations

1. A follow-up appointment at a Down syndrome center
2. Continue infant education and stimulation program
3. Continue family education support

III) Childhood (1- 12 years)

A. History

1. Review parental concerns
2. Review educational programs
3. Inquire about behavioral problems
4. Inquire about hearing or vision problems

B. Physical examination

1. General physical and careful neurological examination
2. Plot height and weight on Down syndrome growth chart

C. Lab

1. Annual thyroid screening with T4 and TSH
2. Hearing screening
2. X-ray cervical spine

D. Consultation

1. Ophthalmology annually
2. Ear, nose and throat when indicated

Appendix A continued

3. Dental annually after age of one or as Dentist recommends

E. Recommendations

1. A follow-up appointment at a Down syndrome center
2. Continue appropriate education and intervention programs
3. Continue family education support
4. Regular exercise and recreational programs
5. Discuss respite care with family

IV) Adolescence (12-18 years)

A. History

1. Review parental concerns
2. Review educational programs
3. Inquire about symptoms of hypothyroidism
4. Inquire about hearing or vision problems

B. Physical examination

1. General physical and careful neurological examination
2. Plot height and weight on Down syndrome growth chart

C. Lab

1. Annual thyroid screening with T4 and TSH
2. Hearing screening
3. Echocardiogram where indicated for mitral valve prolapse
4. Repeat cervical spine film at 18 years of age

D. Consultation

1. Pelvic exam and pap smear for teenage girls
2. Ophthalmology annually
3. Ear, nose and throat when indicated
4. Dental annually after age of one

E. Recommendations

1. Continue appointment at a Down syndrome center
2. Review educational and transitional vocational plans
3. Continue parent education support
4. Regular exercise and recreational program
5. Sexuality education

V) Adulthood (over 18 years)

A. History

Appendix A continued

1. Review for symptoms of dementia, such as decreased memory or care skills
2. Screen for hearing and vision problems
- B. Physical examination
 1. General physical and neurological examination
 2. Gynaecology examination and pap smear
 3. Monitor weight closely for obesity
- C. Lab
 1. Annual thyroid screening with t4 and TSH
 2. Hearing screening
 3. Echocardiogram where indicated for mitral valve prolapse
 4. Repeat cervical spine film at 30 years of age
 5. Pap smear annually
 6. Baseline mammogram at 35 years of age
 - a. Follow-up where indicated by physical examination and family history thereafter
- D. Consultation
 1. Ophthalmology
 2. Dental
- E. Recommendations
 1. Continue appointment at a Down syndrome center
 2. Vocational training and employment
 3. Continue adult education where indicated
 4. Sexuality education
 5. Continue family and education support
 6. Regular exercise and recreation program

APPENDIX B

Life Story of Sandra Hensen

"I was born with Down Syndrome, and that gave me heart and lung problems, and speech problems, and mental retardation, and other problems. When the doctor told my parents what I had right after I was born, he told them they should let him put me in the state hospital and just forget about me, because I would never be any smarter than a three-year-old, and I would never be able to take care of myself, and I would probably die when I was a young teenager. I was lucky to have parents that would not believe the misinformation they got, and they didn't let me go to a state hospital. If they had, probably the doctor would have been right -maybe I wouldn't even have learned to walk or talk, because I sure wasn't the million dollar baby when I was little. They measured my IQ and said it was 30. But I learned to read, I learned how to handle money, I learned how to take the bus, I learned how to live in my own apartment, where I've lived for more than ten years now.

"I have learned that being retarded just means being slow, but nobody really knows how far you can keep going, even if you go slow. The other kids learned how to read when they were six. I didn't. But if my parents and my teachers had decided that because I didn't learn how to read when I was six I'd never learn, I never would have learned. But they believed in me, and I learned how to read when I was 12.

"It used to really upset me a lot that I have DS and all those other disabilities. I remember even when I was learning to take the bus as part of independent living training, I hated to take the bus because I always thought nobody wanted to sit next to me because I looked different. Sometimes I still feel sorry for myself.

"But mostly these days when I think about it I am really angry at the doctor and the other professionals who gave out such misinformation. I am really angry to think that some professional are still handing out that kind of misinformation like in the Baby Doe case, and hundreds of cases like Baby Doe.

Appendix B continued

"The truth is just having DS, or having any kind of mental retardation, doesn't automatically mean you are doomed to a low quality of life. People with mental retardation often do have a poor quality of life, but that's because of the retarding environment where they have to live, the sheltered and segregated places they are sent to spend their days, the false beliefs people have about them, and the lack of help they get to learn how to live a normal life.

"Now I lead a pretty normal life, and in a lot of ways a good quality of life. I'm a little sad because my mother and her new husband just moved away from Sacramento. But I have good friends, and we do things together." (Rosenberg, 1993:179-180).

APPENDIX C
Participant Consent Form

DEAR PARENT

Thank you for agreeing to participate in an interview during which you will talk about your experiences as a parent with a child with Down syndrome.

What you say in the interview will be recorded but will remain confidential and if you are interested in the overall results of the study may ask for a copy of the dissertation from the University of Tasmania.

You are free to withdraw your participation at any time.

If having read the above statement, you agree to being interviewed please sign the following declaration:

I (the participant) have read the information above and any question I have asked has been answered to my satisfaction. I agree to participate in this interview. I also agree that research data gathered for this study may be published, provided that neither my name nor that of my child is used.

Name of participant Date

Signature of participant

I have explained this project and the implications of participation in it to this volunteer and I believe that the consent is informed and that s/he understands the implications of participation.

Name of investigator

Signature of investigator Date

APPENDIX D

A list of the Interview Questions

- 1- Could you please talk about (child's name), and your experiences with her/him?
- 2- When you were told about Ds, did anybody tell you what services your child could receive?
- 3- Have you ever had social or emotional problems because of your child?
- 4- What are some of the things (limitation) that you can not do because of your child?
- 5- What kind of social services (education and health programs) are available to your child?
- 6- Have you faced particular problems when receiving social services (such as early intervention programs) for your child?
- 7- What to you are the specific needs of families who have a child with Ds?
- 8- What factors, if any, do you think might lead to a regression in the quality of life of children with Ds?
- 9- Do you think social services (educational and health programs) reach all children with Ds?
- 10- What factors do you think are important for having a better life for your child?
- 11- Are you satisfied with current social services (educational and health programs) for your child?
- 12- Parents' age, job, education, number of children, and date of birth of family members.

APPENDIX E

A Questionnaire of Mothers' Perceptions

1. Education: Please indicate levels of education for all members of family with a (√). Indicate with an (*) your child with Down syndrome (DS).

Family \ Education	Non-attendance	Primary	Secondary	Tertiary
Mother				
Father				
First Child				
Second Child				
Third Child				
Fourth Child				

2. Date of birth: Please indicate with an (*) your child with DS.

Family \ Date	Year	Month
Mother		
Father		
First Child		
Second Child		
Third Child		
Fourth Child		

3. When did you find out that your child was with DS?
-
-
-
4. Who told you the first time and in what circumstances?
-
-
5. What was your reaction when you learned that your child was with DS?

Appendix E continued

-
.....
6. Did anybody offer counselling or support to you as a parent? Yes No (Circle one) Please explain.
.....
.....
7. When you were told about DS, did anybody tell you what services your child could receive? Yes No (Circle one) Please explain.
.....
.....
8. Have you ever had social or emotional problems because of your child (eg social attitudes)? Yes No (Circle one) Please explain.
.....
.....
9. What kind of social services (education and health programs) have been available to your child?
.....
.....
.....
10. What to you are the specific needs of families who have a child with DS?
.....
.....
.....
11. What factors do you think are important for having a better life for your child?
.....
.....
.....
12. Are you satisfied with current social services (educational and health programs) for your child? Please explain.....
.....
.....
.....

Appendix E continued

13. What factors, if any, do you think might lead to lessen the quality of life of children with DS?

.....

.....

.....

.....

14. Do you think social services (educational and health programs) reach all children with DS?

Please explain.

.....

.....

.....

15. Father's current employment:

16. Mother's current employment:

17. Where do you live? Name of City

State Country

18. Is there further information that you would like to add? If yes, please explain.

.....

.....

.....

.....

APPENDIX F

Example of Coding System

Q.S.R. NUD.IST Power version, revision 3.0.5.

PROJECT: My Project, User Talat.

(2 1 3)	/ Tasmania/family/problem
(2 1 3 1)	/ Tasmania/family/problem/emotion
(2 1 3 1 1)	/Tasmania/family/problem/emotion/unacceptance
(2 1 3 1 2)	/Tasmania/family/problem/emotion/grief and teary
(2 1 3 1 3)	/Tasmania/family/problem/emotion/shock and upset
(2 1 3 1 4)	/Tasmania/family/problem/emotion/no prob
(2 1 3 2)	/ Tasmania/family/problem/social
(2 1 3 2 1)	/Tasmania/family/problem/social/immediate family and relatives
(2 1 3 2 2)	/Tasmania/family/problem/social/people
(2 1 3 2 3)	/Tasmania/family/problem/social/etc.; no prob, adopted
(2 1 3 3)	/Tasmania/family/problem/limitation
(2 1 3 3 1)	/Tasmania/family/problem/limitation/no relation
(2 1 3 3 2)	/Tasmania/family/problem/limitation/tired
(2 1 3 3 3)	/Tasmania/family/problem/limitation/people
(2 1 3 3 4)	/Tasmania/family/problem/limitation/no limitation
(2 1 4)	/Tasmania/family/specific need
(2 1 4 1)	/Tasmania/family/specific need/parents
(2 1 4 2)	/Tasmania/family/specific need/society
(2 1 4 3)	/Tasmania/family/specific need/services
(2 1 4 4)	/Tasmania/family/specific need/specialists
(2 2)	/Tasmania/services
(2 2 1)	/Tasmania/services/parent
(2 2 1 1)	/Tasmania/services/parent/DS info.
(2 2 1 1 1)	/Tasmania/services/parent/DS info./no
(2 2 1 1 2)	/Tasmania/services/parent/DS info./yes
(2 2 1 2)	/Tasmania/services/parent/counselling
(2 2 1 3)	/Tasmania/services/parent/facing prob

Appendix G

Special Schools and early education center

Name: Special School

Location: A city in Tasmania

Established: Oct. 1971

No. of students: 20

No. of Staff: 13

The school was first established in 1971 by the Mental Health Service Commission to provide services for children with severe and profound intellectual disabilities. Changes in 1985 to *The Education Act* stated that all children should attend school, and consequently the center was transferred from the Department of Health to the Department of Education, and moved to its present address in 1987.

Students: There are three age groups; 6-10, 10-14, 14-18 years who attend Special School from 9 am to 3 pm for educational programs. Students may live in group homes. There is only one 15 year old student with Ds whose parents live in another city and visit her at weekends. Two students are autistic, two have cerebral palsy, and the rest of the students are with other kinds of disabilities.

Staff : There are 2 teachers, 6 social trainers, one aide, and four other staff including a driver, a bus aide, and domestics.

Fee: Annual fee is \$90 per student.

Name: A Special School

Location: A city in Tasmania

Established: 1957

No. of students: 50

No. of staff: 21

The school opened for the first time in 1957. The programs were established through the efforts of parents with a child with a disability and volunteers. According to the current principal of the school, in the last five years, there have been tremendous changes in all programs.

Students: The students are in three classes; junior, primary, and senior classes from 6 to 18 years of age. Some of the students are residents at the school and meet their parents only on weekends. Nine of the students are with Ds. There is vocational training for students, and some of them work in a self help workshop. They are paid a small salary for their wood work, which includes drawers, book shelves, chairs, and tables.

Staff: There are nine teachers, seven teacher's aides, and five other staff.

Fee: The annual fee is \$80 for juniors and \$140 for seniors.

Name: Early Special Education Center

Location: A city in Tasmania

Established: 1986

The Early Special Education Center is a Department of Education and the Arts facility. It provides educational services for infants and young children who are at risk of delayed development before reaching school age.

Programs: Services include the following:

- home visits,
- hydro therapy,
- parent and toddler groups, and
- parent education and support programs

Staff: The center is staffed by two teachers, a social trainer, and teacher assistants.

Appendix G continued

In 1995, there were 15 children with Ds in Launceston and the north of Tasmania who benefited from early educational programs by attending the center or having a home visit by a social trainer once a month.

Appendix H

Case Study Reduction

In the following case studies No. 10, 11, 12, 13, 14, 16, 17, 18, 19, in Iran and No. 21, 22, 23, 24, 25, 26, 27, 28, 29 in Tasmania are presented.

CASE STUDY NO. 10

Child's Birth Date: Feb. 1986

Family Background

Ms F is 30 and her husband is 35 years old. Ms F is a home maker and has finished primary school. Her husband is a clerk and has finished high school. They have five children: a daughter aged 12 studying in grade 5 in a primary school, a daughter aged 9 studying in grade 3, a son with Ds aged 7 in first grade, a son aged 4, and a daughter aged 3.

Finding out about Ds

Ms F did not have any problem during her pregnancy. When her child was born, nobody told her anything about her son. When her son was seven months old, one of her husband's friends recommended that they take the child to a doctor. The doctor ordered a karyotype test which later indicated that her son was with Ds. Ms F was very sad when she found that her son was with Ds and cried a lot.

Emotional and social problems

Ms F had emotional and social problems. She felt guilty for having given birth to him, and did not want to take him into public places because she did not like the way that people stared at him.

Social services

Ms F says that nobody told her what services would be available to her child, and she never had any services. Her son is going to the exceptional school. Although there are students with different kinds of disabilities which Ms F is not happy about, she is satisfied that her son is studying.

Mother's perceptions

Ms F believes that negative attitudes of people towards children with DS should be changed, and these children should be allowed to go to ordinary schools. Ms F emphasises financial help to families who have a child with a disability.

CASE STUDY NO. 11

Child's Birth Date: Jan. 1984

Family Background

Ms P is 42 and her husband is 48 years old. She is a home maker and has finished primary school. Her husband is a clerk and finished high school. They have six children: a son aged 18 who has his diploma from a college, a son aged 17 in grade 10, a daughter aged 14 in grade 8, twins 11 years old in grade 5, and a son with DS in grade 2.

Finding out about DS

Ms P did not expect to give birth to a baby with DS, because she had heard that this only happens to old mothers. At hospital, nobody told her anything about her child having DS, but she realised her son was different from her other babies, and she could see that something was wrong with him. Ms P took her son to a doctor who told her that her baby was mentally retarded. The doctor ordered a test and the result of the test indicated that he was with DS.

Appendix H continued

Emotional and social problems

Ms P had emotional and social problems. She felt very guilty and was worried. She says: "I wished that he had not been born and sometimes I wish he was dead". Her main problem was how to tell their relatives that her son was with DS.

Social services

Ms P says that nobody told her about social services, and she had not received any special programs. Her child is going to the exceptional school and the director said that her child will be probably provided with speech therapy. He had speech therapy for the last two years, once every month during school time which Ms P thought was very useful.

Mother's perceptions

Ms P believes that her son was not like her other babies and needed more care, therefore her main limitation was that she had to spend longer time to care for her child. She also believes that the specific need of families who have a child with DS is to be provided with information about DS and for parents to meet each other. She thinks that children with DS should be sent to ordinary schools. Ms P says that people are not used to children with DS, and to see a child with DS for them is a negative and unpleasant thing which may cause regression in the quality of life of children with DS.

CASE STUDY NO. 12

Child's Birth Date : Dec. 1986

Family Background

Ms S is 45 and her husband is 49 years old. She has finished primary school. Her husband has finished high school and is a blacksmith. They have eight children: a daughter aged 15 in grade 8, a daughter aged 12 in grade 4, a daughter aged 9 in grade 3 and a son with DS aged 7 in pre school, a son aged 6, a daughter aged 5, a son aged 4, and a 2-year-old daughter. Her last four children stay at home.

Finding out about DS

When Ms R was 28 years old, she was pregnant with her son with DS. During her pregnancy she felt tired very often. When her baby was born, a nurse who seemed not pleased at all showed him to Ms R and said that he was not normal but mentally retarded. She was upset and took him to a doctor. After a test, she was told that her baby was with DS. Ms R was very sad and did not know what to do.

Emotional and social problems

Ms R had emotional and social problem. She was worried and cried a lot. She says sometimes when her son goes out to play with children, they hurt him and make fun of him.

Social services

Ms R says that nobody told her what services her child could receive, and she did not receive any services.

Mother's perceptions

Ms R does not have any limitations. She thinks parents should have enough information about DS. Ms R says the way some doctors treat parents and their children with DS means that they do not have any place in society. She believes special service programs can improve the life of these children, and that Iranian doctors should have contact with developed countries to find out about the latest research.

CASE STUDY NO. 13

Child's Birth Date: Nov. 1986

Family Background

Ms T is 35 and her husband is 37 years old. She is a home maker and has finished primary school. Her husband has finished primary school too and is a painter. They have eleven children: a daughter aged 19 who has finished primary school and is married, a son aged 18 who has finished primary school and works with his father, a daughter aged 16 who has finished primary school and is married, a son aged 15 who is mentally retarded and finished primary school in an exceptional school and works with his father, a son aged 12 in grade 3, a daughter aged 11 in grade 5, a son with DS aged 9 in grade 2, a son aged 8 in grade 1, a daughter aged 7 who has a mental disability and is in pre school, a daughter aged 5 and a 3-year-old son.

Finding out about DS

Ms T says that a few months after her son with DS was born he was very sick. She took him to a doctor who said that her son was mentally retarded and recommended a special test but she did not have her son tested because she was sure that her son had a problem, and she did not see any reason to pay for information that she already knew.

Emotional and social problems

Ms T does not have emotional or social problems but she is upset with the way that other children treat her son. She says other children make fun of him and he cries. Ms T did not know what was exactly wrong with her fourth child, but that he was mentally retarded. During the program, Ms T got some information about DS.

Social services

Nobody talked about social services for children with DS to Ms T. She knows that her son had speech therapy at the school. One of her daughters, who is mentally retarded, had speech therapy in the exceptional school for girls. She does not think that services such as speech therapy reach all children with DS.

Mother's perceptions

Ms T does not have any limitations except being tired because of so much work at home. She thinks financial help can improve the life of their children.

CASE STUDY NO. 14

Child's Birth Date: Jan. 1986

Family Background

Ms C is 27 and her husband is 40 years old. Ms C has finished grade 9 and is a home-maker. Her husband is a tailor and failed grade 9. They have five children: a boy, aged 9, in grade 3, a boy with DS aged 7 in pre school, a 5-year-old daughter, and 3-year-old twins, a boy and a girl.

Finding out about DS

Ms C had a little difficulty during her pregnancy but went to term. The day after her baby was born, the doctor arranged for a test to be done. Later on she found out that her baby was with DS. She remembers the doctor said to her "nothing can be done, he is not normal". Ms C could not believe what she had heard and cried for a long time.

Appendix H continued

Emotional and social problems

Ms C has emotional and social problems. Her main problem is that her child is teased when other children see him. In addition, her husband's family think that it is Ms C's fault that they have a child with DS. Therefore, she does not see her husband's family as much as she should.

Social services

Ms C says that nobody told her about services for her child, and there is no special service for him. Her son attends an exceptional school.

Mother's perceptions

Ms C believes that parents should respect and love these children, and grand parents should accept them. Likewise, negative attitudes of society should be changed.

CASE STUDY NO. 16

Child's Birth Date: June 1983

Family background

Ms D is 41 and her husband is 57 years old. Both finished primary school. She is a home-maker and her husband is retired. They have nine children; a girl aged 23 who finished grade 9 and is married, a boy aged 20 who finished grade 9 and works as a seller, a boy aged 17 in grade 10, a girl aged 15 in grade 9, a girl aged 13 in grade 6, a boy aged 10 in grade 4 and an -8-year old boy with DS in grade 2, a five year old boy, and a three-year-old boy.

Finding out about DS

Ms D says that her child with DS was born at home when she was visiting her family in a town in the north of Iran. After a few months, she found out that her child was a little different from her other children. When her son was two years old, the doctor said that he was mentally retarded.

Emotional and social problems

Ms D does not have emotional or social problems. She is only unhappy that her child is not normal and that some of the students bother him at school.

Social services

Nobody talked about social services to Ms D. The doctor only said that her son was mentally retarded. When her son was 6 years old, he was referred to the School of Rehabilitation for speech therapy by one of Ms D's relatives who was a social worker. Ms D took him there for a year, once a month. He is short sighted and should wear glasses, but at the school other children take his glasses and make fun of him.

Mother's perceptions

Ms D does not have any limitations. She believes families should be protected by programs such as educating parents and special service programs for children before they begin school.

CASE STUDY NO. 17

Child's Birth Date: Nov. 1983

Family background

Ms P is 37 and her husband is 39 years old. She finished grade 9 and is a home-maker. Her husband finished year 12 and owns a supermarket. They have four children; a girl aged 21 at university, a boy with DS aged 10 in grade 3, a seven year-old son in grade 1 and a four year-old son.

Appendix H continued

Finding out about DS

Ms P says that all her children were born by caesarean section, and her child with DS was born two months early. After three days before she went home, the doctor said to her: "Your child is Mongol". She was upset and cried a lot.

Emotional and social problems

Ms P says that she had emotional problems for a few months because her child was not normal. She had social problems with her relatives because they did not behave well and looked at her child differently, but now it is no longer a problem for her and for her relatives.

Social services

When Ms P was told about DS, nobody told her about social services. Her child has speech therapy at school, but the problem is that he gets colds very easily, especially during winter and therefore can not attend the school regularly.

Mother's perceptions

Ms P prefers not to have much social contact with people outside the immediate family. She believes that the specific needs of families with a child with DS are acceptance by society and by family as well as educating the families, and that it is important to have social service programs for children with DS. She emphasises that negative attitudes of society and inappropriate living environment are factors which might lead to regression in the quality of life of children with DS.

CASE STUDY NO. 18

Child's birth Date: Dec. 1985

Family Background

Ms H is 33 years old and finished primary school. She works as a cleaner in different houses. Her husband was an unskilled worker and had finished grade 4. He was 46 when he died in an accident at work. Ms H has six children; a 16 year old boy who finished grade 9 and works in order to help the family, a girl aged 15 in grade 9, a girl aged 13 in grade 5, a girl aged 10 in grade 4, a boy aged 8 with DS in grade 2, and a 5-year-old girl.

Finding out about DS

Ms H did not have any special problem during her pregnancy. Her baby was born at home. They were living in a town, Tabriz, at that time. After a year she took her child to a doctor, because he was sick. The doctor recommended that they take him to the capital for a [karyotype] test. The result of the test showed that he was with DS. Ms H was very upset and she and her husband decided not to go back to their home town and stayed in the capital.

Emotional and social problems

Although Ms H was upset that her son was not normal, her emotional and social problems were because of her husband's death. She had financial problems, and that was the reason that she and her eldest son had to work.

Social service

Ms H does not receive any kind of social services. She has never been told about available social services. She is happy that her son with DS attends the exceptional school.

Mother's perceptions

Although Ms H received financial assistance from her husband's employer in the past, she has no financial support at present. She was considering going back to her home town in order to get support from her family. She thinks that financial support is the first need of families who have a child with DS.

Appendix H continued

CASE STUDY NO. 19

Child's Birth Date: March 1986

Family Background

Ms and Mr N are both 28 years old and both have finished year 12. She is a home-maker, and her husband is a teacher at a primary school. They have two children; a seven year old son with DS in grade 1, and a two year old daughter.

Finding out about DS

Ms N had a difficult pregnancy. She was tired and had to rest most of the time. Her son was born in a hospital and the doctor told her the day after the birth that her baby was not normal. She could not believe what she had heard. The couple cried a lot. Test results revealed that he was with DS. When Ms N was pregnant with her second child, they decided not to have more than two children, so when their second child was born the couple signed for a tubal ligation.

Emotional and social problems

Ms N had emotional problems for the first year. Then she found him to be a very lovely child and has not had further emotional problems. She still has social problems and prefers not to go into public because of the way that people stare at her son.

Social services

When Ms N was told about DS, nobody told her about social services. She is not receiving any social service programs. Her son attends an exceptional school which he does not like because some of the students bother him at school. He often has colds and ear problems.

Mother's perceptions

Ms N thinks that their living environment is not good, because she believes that children with DS need to have a good living environment, so they have sold their house and will move to a better part of the city in the near future. She also thinks that children with DS are very affectionate and need affection too. She stresses the need for good educational programs too.

CASE STUDY NO. 21

Child's Birth Date: June 1992

Family Background

Ms S. is 29 years old and finished high school. She works part time as a cleaner. Her husband is 32, and finished high school. He works full time as a truck driver. Ms and Mr S have two children: a boy, 7 years old and a girl with DS, 21/2 years old.

Finding out about DS

Ms S says that her pregnancy was not as easy as she had hoped. It was fine up until the labour, but she had to have a caesarean. When she woke up, she saw her husband was there with tears in his eyes. Her husband said to her that something was wrong with their girl, and that the baby was with DS, but Ms S did not mind because she really wanted to have a girl.

Emotional and social problems

Ms S did not have emotional or social problems. In her opinion, her baby does not look any different from other babies. She says: "One of our neighbours who was pregnant came to see me. She looked at me and I told her that my daughter had DS. My neighbour said that she knew".

Social services

Ms S was not given any information at hospital, but the nurses showed her a video. She got information, such as taking her child to location D, through other mothers. Her daughter was attending location D. and having physio therapy at location E.

Appendix H continued

Mother's perceptions

Ms S believes the main thing is that the child should be accepted as everyone else in the family and society, and that these children should have the same education and attend ordinary schools.

CASE STUDY NO. 22

Child's Birth Date: July 1992

Family Background

Ms M is about 24 years old now and has finished high school. She was working until she was 3 months pregnant and since then she hasn't been working outside the home. Her husband is 27 years old. He has finished high school and works full time as a sale assistant. Ms M was 20 years old when she first became pregnant, but she had a miscarriage for unknown reasons. She was 21 years old when her son with DS was born. He is now 21/2 years old. Ms M has a daughter who is 3 months old.

Finding out about DS

The paediatrician told Ms M, the day after her son was born, that he had DS. Every body in the hospital, paediatrician, nurse, and staff, knew before except Mr and Ms M. who talked to the social worker in the hospital. They decided to have him adopted. They left him in the hospital, but after two weeks, they talked to the social worker in the adoption agency, they changed their mind. Then they went back to hospital and picked him up.

Emotional and social problems

Ms M did a lot of crying. Now it does not matter to her that her son is with DS, but she does not like the way that people comment on him. People seem to be noticing him, and she does not want to have a conversation with people about her son.

Social services

When Ms M was told about DS nobody told her what services would be available to her son. Her son had physio for 18 months at location E, and was going there for occupational therapy which Ms M believes was useful. The only problem was that it was hard to get into the program because there was a long waiting list, about one to three months waiting.

Mother's perceptions

Ms M does not feel any limitation due to her son having DS. She thinks that these children should not be treated differently, and that the attitudes of society should be changed.

CASE STUDY NO. 23

Child's Birth Date: Oct. 1991

Family Background

Ms G. is 37 and her husband is 46 years old. She has finished high school and is a home maker. Her husband has a bachelor degree and is a primary school principal. They have four children : a girl, aged 10, a boy, 8 years old, a girl aged 6, and a four year old girl with DS.

Finding out about DS

Ms G was very nervous when pregnant and the doctor gave her tranquillisers. She was worried about the effect of the tranquillisers. When she first saw her baby first, she knew that the baby was different. She saw nurses were whispering to each other and one of the nurses whispered to the doctor. All of the nurses went out of the room and the doctor came in, and told her that her baby was with DS but they had to have her tested. They wanted to take the baby to be weighed. Ms G was

Appendix H continued

worried about them taking her baby away from her because she had heard in the past babies with DS were taken from their mothers. Ms G says when her baby was born, she could see immediately that her baby was with DS. Ms G cried for two or three days.

Emotional and social problems

Ms G does not have emotional problems. She says once she took her baby to her neighbour who is 85. The couple did not want to touch the baby. They asked if she would go to a home later on in the future, and Ms G said no. She explained to them that her child was a treasure. She says sometimes people come to her and say how terrible it is, and through her baby they can see the suffering of mankind, but she has had to prove that her child is special to her husband and herself.

Social services

When Ms G was told about DS, the doctor organised for a lady from the support group to visit her. He also gave her good information. Her child goes to location D. for education and location E for occupational therapy. They used to live in a place which was 25 minutes drive from town. They had to move to town and now they live in a place which is 5 minutes drive from location D Ms G thinks that in some rural areas in Australia, children are not covered by social services.

Mother's perceptions

When her baby was younger, Ms G preferred not to go to parties because her child was not able to do what other children could do, such as walking, and she did not want to compare children with each other. Ms G believes that the first specific need of families who have a child with DS is a good doctor. Her child had two check ups, but the doctor did not pick up that her child needed a heart operation. The physiotherapist noticed it, and when Ms G explained that her child was not all right, the doctor said that it was too late to operate. The doctor finally checked with the hospital in Melbourne. They had to wait six weeks on the waiting list and the whole treatment took ten days. Ms G believes that zinc supplement is good for children with DS but doctors do not recommend it. She gave the supplement to her child when she was one year old, and her appearance improved. She went on to say that attention to diet is necessary, because poor or inappropriate diet may lead to a regression in the child's quality of life. She also believes that love and acceptance by family and society, and the right information about DS for mothers are important factors for an improvement in the life of children with DS.

CASE STUDY NO. 24

Child's Birth Date : Oct. 1990

Family Background

Ms K. has a bachelor's degree and a master's degree in aquaculture. Her husband is a full time technical officer at a university and has an Associate Diploma. Both are 32 years old. They have 3 children: a five year old boy with Ds, a boy aged 21/2, and a seven month old girl.

Finding out about DS

One hour after her son was born, Ms K found out by his appearance that he was with DS. The paediatrician in hospital told her that he had to have a test and the result was positive. A mother from a support group came to visit her. It took Ms K one or two weeks before she was ready to talk to the mother in the support group who gave her some information about DS.

Appendix H continued

Emotional and social problems

It took Ms K a year to get used to the idea. She did not know what was normal. She had to go to different doctors, and her son was not breastfeeding which was a little difficult. The only thing that she had trouble with was her prenatal education class. She was the first to have a baby and she felt odd. All children in that class were normal and all were breast feeding except her child. So she stopped attending.

Social services

When she was told about Ds, she was not told much about available services for her son. The only booklet given to her by the support group was out of date with old pictures. Then the paediatrician who had a son with DS asked her permission to call a physio from location E. Her son was going there until he started walking. Ms K knew about location D. through the support group but did not want to go, so she sent her parents first. They said that it was a wonderful place and then she went. Since then, every Friday morning she meets parents with their child with DS or other disabilities there. Her son attends a child play center half a day weekly. Ms K takes her son to a paediatrician once every six months. Her son is very sensitive to cold and has course after course of antibiotics especially in cold weather. His major problem is very low muscle tone. She believes that children with DS in rural areas are not probably covered by social services.

Mother's perceptions

Ms K says that because her son is slow developing they can not go to some places. For instance, they would like to go to a restaurant but because he can not eat they could not go. Ms K thinks it is important to have a hospital pack for mothers which is currently being developed. It includes medical needs information and useful phone numbers.

CASE STUDY NO. 25

Child's Birth Date: 20 Nov. 1992

Family Background

Ms M is 36 years old. Mr M is 39 years old. Their daughter is 2 and half years old and is the only child in the family. Ms M has a bachelor degree and is a professional, a physio therapist. Her husband has finished college and is working full time at a casino.

Finding out about DS

Ms M was in labour for three days until her daughter was born. After an hour, she was told by a paediatrician that he had to take a blood test for Ds. Ms M looked at her child and she could see that her baby was with DS. Ms M had no support from the nursing staff. She was put at the end of the ward.

Emotional and social problems

Ms M had problems for the first four months. It took her eight months to cope with the problem. Her mother thinks this was a terrible thing to happen to her, and she was not a help to Ms M.

Social services

Nobody talked about social services to Ms M. One of the nurses told her that a mother from a support group could come to talk to her. But it was difficult for Ms M because the mother was one of Ms M's client's mother, and Ms M needed to see a social worker, or a psychologist. Nobody contacted Ms M. She had to make contact with everybody. Her child attends location E twice a week because Ms M feels strongly that therapy is important and the role of education is later. She had home visits by location D. She has not sent her child to location D., because she believes children who go to location D are often children with behavioural problems, and will have no communication. So it will not help her child. Her daughter goes to a regular play group once a week. Ms M says the problem is to get

Appendix H continued

regular occupational therapy because there is only one center in Launceston, and there is a waiting list for three or four months in order to enter in the program. Ms M thinks the further out from the center, the more difficult it is to get services, and living out the town is more difficult. She believes that parents in her city do not have good access, as in Sydney or Melbourne, to social services.

Mother's perceptions

Ms M thinks she does not have any limitations now. She believes knowledge is the most important thing for parents, and it will be very helpful for parents to know there is a social worker. There is no social worker at location E or location D. All support is through parents who are not professionals, although parents need professionals to be involved. Ms M thinks it is important to educate the community about DS. Even some of the professionals need to be educated as well. One of the factors is that some paediatricians and GPs and many health professionals, including some of the therapists working in the area, have poor expectations of these children with DS and do not realise the actual potential of children. Parents do not realise what is really available until they see what other parents do. Ms M adds that an important factor for having a better life for children with DS is to give opportunities to children in order to be able to work later on and have an independent life.

CASE STUDY NO. 26

Child's Birth Date: Oct. 1987

Family Background

Ms E. is 33 years old and her husband is 39 years old. They have three boys; 9, 8, and 4 years old. Her eight year old child is with DS. Mr E. has finished college and is working full time as a clerk. Ms E. is a nurse.

Finding out about Ds

Ms E miscarried twice and her child with DS was her fourth pregnancy. When her child with DS was born, the paediatrician told her that he may be with DS. Her reaction was that she could not have a child with DS because she was 26 years old at that time and was not old. After six weeks she got the result of blood test and knew that her child was with DS.

Emotional and social problems

It took Ms E six weeks to cope with her new situation as a mother of a child with DS.

Social services

When she was told about Ds, nobody told her about available services. There was nothing (no special services for children with Ds) in her city at that time. Ms E says when her child was six weeks old, she contacted location E to make an appointment. Her son had physio and occupational therapy there. When her child was three years old, he attended location D once a week. He also had a home visit once a month for an hour by location D. There was also a respite care program. When her son was eight months old, he got a host family. He was going once a week on that program. Her son is still in the respite care program. Ms E thinks that the waiting list for occupational therapy was very long, and there was not a group visit at hospital at that time. Ms E started a group visit at hospital. She says there are some mothers who do not want to have information about DS for their child, and nobody knows them.

Mother's perceptions

There is no limitation for Ms E. She thinks the specific needs of families who have a child with DS is to have information about DS, and acceptance of their child by family and the community.

CASE STUDY NO. 27

Child's Birth Date: July 1991

Family Background

Ms S is 38 years old and is a home maker. Her husband is 42 years old and works as an accountant. His qualifications are equivalent to a Bachelor's degree. Ms S' qualifications are equivalent to a Bachelor of Nursing. They have 3 children: a boy aged 11, a four year old girl with DS, and twins, aged three.

Finding out about DS

When her child was born she realised after a few minutes that she was with DS. Ms S had some knowledge about DS because she had been an auxiliary nurse, but she had not seen children with DS in society. Her child was in hospital for a month because she had a problem feeding.

Emotional and social problems

Ms S was upset when she was born, but she did not have emotional or social problems later on.

Social services

At hospital, a mother from the support group gave her some information about location D, and location E. Her child had home visits from location D beginning when she was six weeks old for 12 months. Then she started to go there once a week. She had physio therapy when she was a couple of months old. She started to go to a play group run by TAFE when she was 18 months old. There is a long waiting list for this play group. The physio therapy was stopped when she was two years old, and she practices at home. Ms S would like her daughter to go to ordinary school. She spoke to a mother whose child with DS was at ordinary school. This mother said that she was having problems with her child at school because other parents did not like her being in the school. Ms S wishes that occupational therapy was not cut for her daughter.

Mother's perceptions

Ms S does not have any limitations except that when she takes her other children to Young Men Christian Association, her daughter can not go there. She believes that parents should spend time for their child with DS, especially with learning every day things. Likewise, children with DS should be integrated into ordinary schools.

CASE STUDY NO. 28

Child's Birth Date: Nov. 1985

Family Background

Ms N is 40 and her husband is 44 years old. She is a trained nurse. She finished grade 9 in high school and worked until the age of 20. Then she worked in a hospital for 3 years, and for a period of 12 months in maternity. She works part time as a community health nurse and is currently studying by correspondence for a bachelor's degree. Her husband is a trained psychiatric nurse, and works part time at a hospital. They have two boys: their first child with DS is 9 years old in grade three, and the second child is 7 years old in grade one.

Finding out about DS

Ms N was going to have her baby at home but her midwife told her to have the baby in the birth center which is a center attached to the hospital. She had a long labour, 23 hours. When she saw her son she realised that he was with DS. She did not know about it. Her midwife did not say anything to her. Later, the doctors did not say anything either. After six weeks, one of the staff at the child health system suggested that she have her son tested. After she got the result of the test, she went through grieving and was upset.

Appendix H continued

Emotional and social problems

It took Ms N three months to cope with her new situation. She had grief which she says is not unusual. She had to change his school in order not to have problems with the school.

Social services

At hospital nobody told her about social services. Later on, she had to ask everybody. She wrote letters to England, and the US, and since her parents live on the mainland she went there to get information about available services. Location D did not give her son any service program because Ms N was living in a rural area, but she found the occupational therapy at location E helpful. Ms N talked to a friend who knew a mother whose child with DS was four years older than her child.

Through her experience Ms N went to the Education Department to find an ordinary school for her son. She was working with her son at home through the books that she got from the mainland. Her son had his tongue reduced in Melbourne when he was two years old because it was hanging out. Ms N says that it is hard to say if it was good for his speech but his appearance is better now. Because Ms N was living in a rural area she did not have the same access as mothers who were living in a city. Ms N thinks that there were not many services when her son was born, and her son did not have access to even this limited programs.

Mother's perceptions

Ms N does not have any limitations except that she says sometimes it is a big problem to go out with him. She believes that early intervention programs are necessary right from the birth which include gross motor skills. These children should have an opportunity for a better education, and changing the attitudes of society is important for the improvement of their life.

CASE STUDY NO. 29

Child's Birth Date: March 1990

Family Background

Ms B is 45 years old and her husband is 47. Ms B has her high school certificate and her husband who is a teacher at TAFE has the equivalent of a Bachelor's degree. They have six children, a girl aged 25, a girl aged 23, a son aged 9, a girl 7 years old, a girl with DS and is 5, then a 16 month old daughter.

Finding out about DS

When her child was born, Ms B saw a nurse have a short talk with the doctor. Then they disappeared very quickly. When she looked at her baby she knew that her baby was with DS, but she did not want anyone necessarily to say anything. Then the paediatrician told her about DS. She was worried about whether her baby could see or hear properly or if she would be able to feed her baby.

Emotional and social problems

She cried a lot, but her emotional problem was very short but did not go away completely. Every now and then she felt sadness. She realised that she could create a social problem for herself. She felt better to tell neighbours that her baby was beautiful and was with DS. She says educated people, professionals who saw her daughter, were a little upset.

Social services

When Ms B was at hospital, a mother from the support group saw her briefly. She was also contacted by location D, and her child had a home visit from location D once a week for an hour until she was three years old. She began physio therapy at location E when she was one month old once a week for 18 months until she could walk. She began speech therapy when she was two and half years old at location D, but it was an assessment not a regular session. When she was three and half years old, she started occupational therapy at location E. She goes to a local school two days a week. She does not have a special health problem except that her teeth are not straight and she needs orthodocny later on.

Mother's perceptions

Her limitation is that she can not work because her child needs more attention. Ms B believes that the specific needs of families who have a child with DS is to have knowledge about DS, and society should accept these children, and encourage families to keep children with DS as part of the family. She thinks the attitudes of some professionals are wrong which may be a regression factor in the quality of life of children with DS. Ms B knows a mother who gave birth to a child with DS. The doctor said to the mother that the baby should not have been born, and the mother grieved for a few months.